A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis

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"It's definitely challenging when you feel so horrible on the inside when you're really, really sick and people are like, oh, you look great. With your illness, when people don't see it, it's really hard to deal with that."

- Jasmine

"It's really important that the counsellor is able to differentiate that I am not the disease and maybe if I'm there and having challenges, they stem somehow from CF, but that's not the only thing I want to be there to talk about."

- Kallie

"While CF clinicians are no doubt experts in cystic fibrosis, we are the experts on where the 'rubber hits the road' in CF care. Having a voice and a vote ensures that guidelines are feasible and more likely to be accepted by the wider CF community."

(Hempstead, 2020)

"In terms of the framework, I really liked the idea of incorporating us in the process, especially early on even when it was just you know, talking about we're thinking about doing focus groups. What do you think of that? It felt like I would actually believe you that you care about our answers and care about our opinion."

- Charlene

"I hear my voice in the framework … I have noticed a change in experience in clinic regarding mental health since sharing it with the team."

- Veronica

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Dedication

This thesis is dedicated to all persons living with cystic fibrosis.

We see you.

We hear you.

You are not your disease.

You matter.

Live. Life. Full.

Acknowledgements

I am grateful to the 30 stakeholders – CF co-researchers, CF patients and CF interdisciplinary team members – who have participated in this study and in the development of The Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis. Thank you to Chloe, Kieran, Chad, Doris, Julia, Katrine, Ali, Kseniya, Allie, Jessica, Justin, Jonathan, Anne-Marie, Ena, Shawn, Karen, Christina, Sarah, Julie, Annie, Sarah, Smita, Mel, Elize, Kelsey, Victoria, Susmita, Kristina, Matt, and Melanie. Collectively we have created a framework that is rich and meaningful and impactful. As promised, I remain dedicated to "getting the word out" regarding CF and mental health and the framework, even beyond our clinic doors.

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Abstract

Persons with cystic fibrosis (CF) struggle with anxiety and depression at rates two to three times higher than the general population which can negatively impact their physical health. They can feel misunderstood and shut out in counselling and psychotherapy sessions, at CF clinic appointments and within medical systems, when it comes to adequately understanding and addressing their mental health. There is a gap in the CF - specific counselling and psychotherapy research literature for robust participatory action research (PAR) designed by and for those with CF in alignment with the disability slogan, "nothing about us without us," as well as for plain language guidelines even while it has been shown that this would facilitate uptake in target groups and implementation within systems. The aim of this study has been to provide a fuller understanding of the experience of individuals with CF and to develop a plain language Patient - Centred Framework for Counselling and Psychotherapy in alignment with their needs. A purposive representative sampling plan was employed to select co-researchers for three focus groups comprised of persons with CF at various phases of their disease process and human developmental stage - cystic fibrosis related diabetes (CFRD); CF aged 39 +; CF aged 18-29. This study utilized The Bridge Model, ™ a community based participatory action research (CBPAR) approach of patient engagement, and the four steps of PAR -planning, action, observation, and reflection - and therefore patient participants were involved as co-researchers in every aspect of the project inclusive of co-facilitating focus groups. Semi-structured interviews were also conducted to get a rich picture of the personal experience of individual co-researchers as well as their needs regarding counselling and psychotherapy that they might not share in a focus group setting. Data analysis of the focus groups and semi-structured interviews was conducted utilizing Interpretative Phenomenological Analysis (IPA). A draft framework was developed based on the findings, and

iterations were shared with key stakeholders, CF co-researchers, CF clinic patients and members of the CF interdisciplinary team, integrating their feedback until all were satisfied with the outcome. The outcome of our study is a plain language Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis, outlining preferred therapist attitudes, knowledge, and skills as well as a note to our CF clinic team, which has developed into a quality improvement project for our Ottawa Hospital Adult Cystic Fibrosis Clinic helping us to better address our patients' mental health needs. We hope that it can be of benefit to other CF counsellors/psychotherapists and CF interdisciplinary team members.

Introduction

One billion people worldwide live with a disability. The vast majority of those with disabilities have a non-visible disability (Ontario Accessibility Laws, 2018; World Health Organization (WHO), 2016). Non-visible disabilities are characterized by symptoms which include debilitating pain, fatigue, dizziness, cognitive dysfunctions, learning differences, mental health problems, as well as hearing and vision impairments (Adams et al., 2010; The Americans with Disabilities Act (ADA), 2008; Davis, 2005; Invisible Disabilities Association (IDA); National Rehabilitation Information Center (NARIC), 2010; the Ontario Human Rights Commission (OHRC), 2016; WHO, 2016). Throughout history, persons with disabilities have long experienced marginalization and inhumane treatment because of disability being equated with human deficiency (Adams et al., 2010; OHRC, 2016; Shaw, 2012; Zola, 1993). To protect the rights of persons with disabilities, treaties between countries and protective legislation have been passed including The United Nations' Convention on the Rights of Persons with Disabilities (CRPD) in 2006, the Ontario Human Rights Code (HRC) enacted in 1962, the Rehabilitation Act of 1973 (U.S.), the Canadian Charter of Rights and Freedoms of 1982, and the Americans with Disabilities Act (ADA) of 1990 (Adams et al., 2010; OHRC, 2016; Shaw, 2012). Whilst definitions of disability may vary in the United States and Canada, both The Americans with Disabilities Act and the Ontario Human Rights Code explicitly include those with non-visible illness/disabilities (ADA, 2008; Adams et al., 2010; OHRC, 2016; Shaw, 2012). The Ontario Human Rights Code also expounds upon the situation of those with progressive and/or acquired non-visible illness/disabilities (OHRC, 2016). I shall elaborate on this subject in the chapter of this thesis entitled, "history of disability, the law, and definitions of disability."

Persons with disabilities are faced with physical and social barriers as well as dominant ideologies that posit "the myth of bodily perfection" or the requirement to meet able-bodied standards (Bassler, 2014; Davis, 2005; Lingsom, 2008; Shakespeare, 1996; Stone, 1995, p. 413; Valeras, 2010). They are socialized by dominant models of disability pervasive in society– the medical model, the social model and the post-structural model chief among them– which characterize their experience differently and have an impact on their identity, sense of self and behavior (Ashby, 2011; Bassler, 2014; Cornish et al., 2008; Davis, 2005; Shakespeare, 1996, 2005; Shakespeare & Watson, 2001; Smart & Smart, 2006; Stone, 1995, Stuntzner & Hartley, 2014; Valeras, 2010). In as much as counsellors and psychotherapists[1] have enculturated these models, our practices may be profoundly affected which in turn impacts our clients[2] (Cornish et al., 2008; Johnson, 2011; Smart & Smart, 2006; Stuntzner & Hartley, 2014; Valeras, 2010). It is incumbent upon counsellors and psychotherapists to familiarize ourselves with the foremost disability paradigms to better understand clients' experiences and to reflect upon where we situate ourselves in our practices (Olkin, 2007; Valeras, 2010). The chapter of this thesis entitled, "dominant models

[1] In this thesis study counselling and psychotherapy are viewed as interrelated but also may be distinctive as defined by the Association for Counselling and Psychotherapy and the College of Registered Psychotherapists. According to the Association for Counselling and Psychotherapy "counselling addresses wellness, relationships, personal growth, career development, mental health and psychological illness or distress" (https://www.ccpa-accp.ca/profession/). According to the College of Registered Psychotherapists "a member is authorized to treat, by means of psychotherapy technique delivered through a therapeutic relationship, an individual's serious disorder of thought, cognition, mood, emotional regulation, perception of memory that may seriously impair the individual's judgement, insight, behavior, communication and social functioning" (https://www.crpo.ca/definitions/). Differences between counselling and psychotherapy may also relate more to the individual counsellor's or psychotherapist's training and interests and to the setting in which they work, rather than an intrinsic difference in the two activities (https://www.ccpa-accp.ca/profession/).

[2] In this thesis study the terms client and patient are used interchangeably depending on context (i.e., community or hospital setting) and authors' and co-researchers' own words.

of disability and the relevance to persons with non-visible illness/disabilities and progressive and/or acquired non- visible illness/disabilities," expounds upon these ideas.

Persons with non-visible illness/disabilities have experiences that are unique from those with visible illness/disabilities which influences their mental health, identity, existential and spiritual issues. Persons with progressive and acquired non-visible illness/disabilities[3] will need to grieve, adjust to their impairment(s) and endeavor to find meaning and purpose in life (Gordon et al., 1998; Graham et al., 2008; Gray & Fossey, 2003; Hareide et al., 2011; Hoppe, 2013; Lingsom, 2008; Lorenz, 2010; Mueller et al., 2020; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Valeras, 2009, 2010; Warnecke, 2017). They may ask themselves who they are now that they are no longer able to perform as before and struggle with their roles in families, workplaces, and society (Graham et al., 2008; Gray & Fossey, 2003; Lorenz, 2010; Mueller et al., 2020; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013). Viktor Frankl's logotherapy provides some guidance in terms of how to help when meaninglessness becomes foreground in client's lives (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Frankl et al., 2010; Pattakos, 2010). The chapter

[3] In this thesis, I refer to the terms disability, non-visible illness/disability and progressive and/or acquired non-visible illness/disability judiciously moving from the general to specific in alignment with the language of the authors of conceptual articles and research studies in describing their subject population. Disability is used broadly by some to describe all those who are not able bodied by society's standards (Bassler, 2014). Non-visible illness/disability refers to all those with impairments that are not obvious to the casual observer and whose functioning falls on a spectrum from illness to disability dependent upon a multitude of factors including physiology and societal barriers (Valeras, 2010). Those with a progressive and/or acquired non-visible illness/disability more specifically live with a health condition that gets worse over time, is initially non-visible, falls on a spectrum from illness to disability and may or may not have been diagnosed later in life, for example, CF (Mueller et al., 2020). The main research question includes the more general non-visible illness/disability as persons with CF in our study seem to refer to themselves with this broader moniker rather than the more specific progressive and/or acquired non-visible illness/disability, although the latter is descriptive of their lived experience.

entitled, “persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities: mental health, identity, existential and spiritual issues” delves into these concerns in detail.

Disability is often misunderstood by counselling professionals and psychotherapists as well as society (American Psychological Association (APA), 2012; Cornish et al., 2008; Johnson, 2011; Oliver, 1995; Olkin, 2007; Stuntzner & Hartley, 2014). Cultural competence and cultural humility are important movements in the field of counselling and psychotherapy, and when applied to persons with disabilities, can yield efficacious results (Artman & Daniels, 2010; Barsky, 2018; Chu et al., 2016; Cornish et al., 2008; Olkin, 2007; Warnecke, 2017; Waters & Asbill, 2013). Guidelines for counselling and psychotherapy may assist therapists in becoming more culturally competent by providing them with vital information regarding the many voices, problems, strengths, and abilities, of those with disabilities thereby enhancing the effectiveness of their interventions (APA, 2012; Stuntzner & Hartley, 2014). Clinical guidelines are required particularly for populations with complex co-morbidities such as those with progressive and/or acquired non-visible illness/disabilities, to improve practices and health care outcomes (Bayliss et al., 2008). Whilst there exist suggested practice guidelines for persons with disabilities, it is unclear to what extent they are applicable to those with non-visible illness/disabilities and progressive and/or acquired non-visible disabilities and have been proposed by researchers in various disciplines employing principally qualitative and quantitative methodology (APA, 2012; Valeras, 2010). There is a gap in the research literature for PAR in the field of counselling and psychotherapy with persons with disabilities, and for plain language guidelines developed by and for them, in alignment with the disability slogan, “nothing about us without us” (Ashby, 2011; Balcazar et al., 2004, 2006; Borg et al., 2012; Kidd & Kral, 2005; Lezzoni & Long-Bellil, 2012;

Minihan, 2004; Olkin, 2007, p.10; Parkinson, 2006; Spong & Waters, 2015). Knowledge constructed without the equal participation of those effected by a problem can only be partial knowledge. Therefore, there is a need for guideline development inclusive of the voices of end users of counselling and psychotherapy services (Kidd & Kral, 2005; Pakhale, Kaur et al., 2016; Pakhale et al., 2018). Whilst not directly in the field of counselling and psychotherapy this researcher outlines three foundational examples of PAR with persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities as example of this methodology yielding rich suggestions for service providers relevant to the field (Deegan, 2005; Lorenz, 2010; Riecken et al., 2005). The gap in the research literature for robust PAR studies by and for those with disabilities in the field of counselling and psychotherapy and the three foundational examples of PAR may be found in the chapters entitled, "counselling and psychotherapy with persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities: suggested practices, guidelines, and a gap in the research literature" and "three foundational examples of PAR with persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities."

CF is the most common genetic illness/disability with 70,000 persons impacted across the globe. CF negatively effects many systems throughout the body, principally the lungs, and can be characterized as a spectrum disorder as symptoms can fluctuate and are unique to each individual. CF has acquired aspects as comorbidities such as CFRD can develop, and many are diagnosed later in life (Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Maras et al., 2018; Mueller et al., 2020). Whilst individuals with CF share common mental health, identity, existential and spiritual issues as others with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities they have characteristics which are specific to them and impact their

emotional well-being. Persons with CF experience a prevalence of anxiety and depression compared to the general population, which can negatively impact their physical health (Bathgate & Barboa, 2021; Berlin et al., 2005; Bone, 2017; Borschuk et al., 2016; Canda, 2001; Goldbeck et al., 2014, 2015; Heltshe et al., 2017; Heo et al., 2021; Hogg et al., 2006; Hjeln et al., 2020; Horky et al., 2017; Ladores, 2020; Langawai et al., 2020; Macdonald et al., 2019; Maras et al., 2018; May et al., 2021; Modi et al., 2010; Mueller et al., 2020; Nutting & Amos, 2020; Oliver et al., 2014; Pakhale et al., 2014, 2015; Quittner et al., 2014, 2015, 2016; Sawicki et al., 2008; Sharma et al., 2020; Smith et al., 2016; Trandel et al., 2019; Varilek & Isaacson, 2020). Counselling and psychotherapy have been shown to improve symptoms of anxiety and depression in those with chronic illness therefore making it imperative to better comprehend these practices in the field of CF (Besier & Goldbeck, 2012; Cronly et al., 2019; Duff, 2015; Garcia et al., 2018; Goldbeck et al., 2014, 2015; Hempstead, 2020; Maras et al., 2018; Mueller et al., 2020; Pakhale et al., 2015; Quittner et al., 2014, 2015, 2016; Smith et al., 2016). Research into CF-specific psychotherapeutic interventions as well as guidelines in both the United States and Canada has been developed and more recently has taken a participatory turn, which is in alignment with the appeal of persons with disabilities as well as disability theorists (Balfour et al., 2014; Busetto et al., 2020; Carman et al., 2013; Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Deegan, 2005; Friesen et al., 2019; Hempstead, 2020; Hoppe et al., 2020; Kazmerski et al., 2018; Kidd et al., 2017; Kramer-Golinkoff, 2014; Lorenz, 2011; Macdonald et al., 2019; Minihan et al., 2004; Pakhale et al., 2014., 2015; Quittner et al., 2016; Ramos et al., 2019; Reiken et al., 2005; Sabadosa & Batalden, 2014; Verkleij et al., 2021; White & Verhoef, 2005). This researcher has sought to build upon this participatory turn by fully employing PAR, including persons with CF in every aspect of this study and in the development of A Patient-Centred Framework for Counselling and Psychotherapy with

Persons with a Non-Visible Illness/Disability: Cystic Fibrosis. To include those with CF in the development of a framework for counselling and psychotherapy by and for them fills a gap in the research literature. It ensures that the framework is relevant and meaningful. It ensures culturally competent and cogent practices. The case for a patient-centred framework for counselling and psychotherapy with persons with a non-visible illness/disability: cystic fibrosis will be elaborated upon in the chapter of the same name in this thesis.

This studies' main research question is, what would constitute A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis? The methodological details of this study will be elaborated upon in-depth in the methodology chapter followed by the chapter on findings. Interpretative phenomenological analysis (IPA) has been employed within (vertically) and across (horizontally) three focus groups and six semi-structured interviews comprised of persons with CF at various phases of their disease process and human developmental stage. The findings reveal a rich account of the day-to-day experiences of those with CF as well as their requirements for counsellors and psychotherapists - attitudes, knowledge, and skills, and a note to our CF clinic team - that constitute the framework. The final chapters of this thesis comprise the discussion and conclusion, inclusive of the plain language patient-centred framework, challenges, limitations and acknowledged strengths of this study, and clinical and theoretical importance/practical implications/next steps.

Chapter 1: History of Disability, the Law and Definitions of Disability

Throughout history, persons with disabilities have long experienced marginalization and inhumane treatment as a consequence of disability being equated with human deficiency, thereby labelled "misshapen" and "defective" (Adams et al., 2010; OHRC, 2016; Shaw, 2012; Zola, 1993, p. 171). This negative treatment has included all manner of abuse, from euthanasia policies,

involuntary sterilization, and institutionalization to barriers to accessing educational and employment opportunities and restrictive immigration policies preventing people with disabilities entry (Adams et al., 2010; Barnes, 2012; Davis, 2005; OHRC, 2016). For example, in Canada, from 1929 to 1972, when finally forced sterilization legislation in Alberta and British Columbia was repealed, over 2,800 people with mental health and physical disabilities were sterilized without their knowledge or consent (OHRC, 2016). Canadian immigration laws have also been restrictive in the past to persons with perceived intellectual or developmental disabilities. Even recently, despite changes to federal legislation, there have been ongoing barriers for people with disabilities who wish to immigrate to Canada, for example, in 2016 a family was denied permanent residence status because their child has Down Syndrome (OHRC, 2016). Positive change began post World War II with the return of wounded veterans and the advent of the rehabilitation movement, which advocated for restoration rather than repudiation (Adams et al., 2010; Barnes, 2012; Shaw, 2012). In North America in the 1960s forward, disabled persons benefited from the larger civil rights movement and protective legislation was passed such as the *Ontario Human Rights Code* (HRC) enacted in 1962, the Rehabilitation Act of 1973 (U.S.), the *Canadian Charter of Rights and Freedoms* of 1982, and the Americans with Disabilities Act (ADA) of 1990 (Adams et al., 2010; OHRC, 2016; Shaw, 2012). Internationally, the United Nations adopted The United Nations' Convention on the Rights of Persons with Disabilities (CRPD) in 2006 and Canada signed on in 2007. In the 1960s most Canadian provinces also began a process of deinstitutionalization which many hailed as a way forward (OHRC, 2016). On April 16, 2018, the minister of Immigration, Refugees and Citizenship Canada announced changes to the medical inadmissibility regime to "better align with Canadian values and reflect the importance that the Government places on the inclusion of persons with disabilities" (Citizenship Canada, 2018, para. 1).

Despite legislation and changing attitudes, however, many persons with disabilities continue today to struggle to find adequate and accommodated employment, suitable living opportunities, and equal footing in health care systems (Munyi, 2012; Peacock et al., 2015). Many studies show that persons with disabilities do not benefit in the same way as their non-disabled counterparts from patient-centred care which negatively impacts health outcomes (Bassler, 2009; Kirschner, 2009; Lezzoni, 2006; Lezzoni & Long-Bellil, 2012; Minihan et al., 2004, 2011; OHRC, 2016; WHO, 2016). In the health care realm, persons with disabilities find clinicians: 1) patronizing; 2) making negative assumptions about the quality of their lives; 3) focusing on the disability rather than the person; 4) and not attempting to understand the entirety of their lives including their experience of illness, goals, aspirations, strengths, and abilities (Deegan, 2005; Minihan et al., 2004; Riecken et al., 2005).

Today, Canada has a human rights regime designed to protect individuals from discrimination. The federal government and each of the provinces and territories have adopted legislation to protect individuals. The various legislatures have also established commissions to investigate and tribunals to adjudicate claims of discrimination that include claims based on unfair treatment of persons with disabilities. Both the federal government and the provinces and territories exercise authority within their constitutionally divided jurisdictions. Their respective human rights regime applies to those matters in their exclusive areas of responsibilities (Kanter, 2015). Although the United States is considered a pioneer in disability rights law, the American legal regime takes a narrower view to the protection of people with disabilities than the approach adopted in Canada (Kanter, 2015). The Supreme Court of Canada, in its unanimous and landmark decision in Eldrige v. British Columbia, [1998] 3 SCR 624, distinguished its view of discrimination from that of the Supreme Court of the United States. The Court pointed out that the American

regime requires a discriminatory intent to find an equal protection violation under the Fourteenth Amendment of the U.S. Constitution whereas the Canadian view is "to promote the objective of the more equal society." (Kanter, 2015, p. 88). Kanter (2015) concludes that the Court's:

> Recognition of the importance of ensuring protection for substantive equality as well as dignity for people with disabilities stands in sharp contrast to some U.S. court decisions which refused to even consider the humiliating effect of allegedly discriminatory conduct on the individual with a disability as a violation of the right to equality (p. 89).

The Americans with Disabilities Act (ADA) was adopted in 1990. According to the United States Department of Justice, a person with a disability is defined as follows:

> A person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment (ADA, 2008, p. 1; Shaw, 2012, p. 9).

Major life activities initially referred to activities of daily living such as feeding, bathing, dressing, and grooming but was expanded in a 2008 amendment to be more inclusive of those with non-visible disabilities (Adams et al., 2010; IDA; Shaw, 2012). Major life activities now include, "learning, reading, concentration, thinking, communicating and working" (Adams et al., 2010, p. 459; IDA; Shaw, 2012, p. 9). The ADA is now also inclusive of persons with some psychiatric disorders, for example, major depressive disorder, as well as those with learning disabilities, hearing or speech impairments and other health or physical impairments. Some impairments not included in the ADA include current substance abuse (Shaw, 2012; Wing & Sue, 2008).

The Canadian regime for the protection of people with disabilities is explicitly guaranteed under our Constitution. Section 15 of the Canadian Charter of Rights and Freedoms, which applies throughout Canada, reads as follows:

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability (Canadian Charter of Rights and Freedoms, The Constitution Act, 1982).

Ontario's human rights legislation is called the Ontario Human Rights Code (HRC) and was adopted in 1962. The Ontario human rights system consists of the Ontario Human Rights Commission (the Commission), the Human Rights Legal Support Centre (the Centre) and the Human Rights Tribunal of Ontario (the Tribunal). The Centre provides information and advice to people who feel that they may have faced discrimination (e.g., at work or while securing accommodations or goods and services). Individuals who believe that their employer or landlord violated their rights may make a complaint to the Tribunal. The Commission works on the roots of discrimination to effect systemic change and may also become involved in human rights cases before the Tribunal. The Ontario Human Rights Code contains specific provisions dealing with discrimination based on disability. The Commission states that defining disability is a "complex, evolving matter" that "covers a broad range and degree of conditions" that may have been "present at birth, caused by an accident, or developed over time" (OHRC, 2016, p. 8). The Commission has published two specific policies to inform the public about discrimination based on disability and provides specific guidance on "Non-evident disabilities" (synonymous with non-visible illness/disabilities):

Section 10 of the Ontario Human Rights Code defines disability as follows:

> (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,
>
> (b) a condition of mental impairment or a developmental disability,
>
> a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
>
> (d) a mental disorder, or
>
> (e) an injury or disability for which benefits were claimed or received under the insurance plan established under the Workplace Safety and Insurance Act, 1997 (OHRC, 2016, p. 8).

Section 10 of The Ontario Human Rights Code (HRC) includes mental health disabilities and, in Canada, persons with addictions to drugs or alcohol are also protected (OHRC, 2016). It is acknowledged in the HRC that persons with mental health disabilities and persons with addictions face substantial stigmatization and barriers which can exacerbate stress and therefore can worsen a person's condition. This may mean that persons with these conditions do not reach out for help for fear of being marginalized and labelled. This has led the Ontario Human Rights Commission to develop a Mental Health Policy released in 2014 to provide guidance to organizations on how to assess and resolve human rights issues based on mental health disabilities and addictions (OHRC, 2016, p. 13).

The Ontario Human Rights Commission's view is that disability should be interpreted in broad terms that include both present and past conditions, "as well as a subjective component, namely, one based on perception of disability" (OHRC, 2016, p. 8). The Commission also takes the position that an anticipated disability would be covered by The Ontario Human Rights Code, for example, where a person does not currently have a disability but will eventually develop one and is treated adversely because of the perception that the person will ultimately become a burden, pose a risk or require accommodation because they will eventually develop a disability (OHRC, 2016, p. 8).

The Ontario Human Rights Commission refers to "Non-evident disabilities" as follows:

> The nature or degree of disability might render it 'non-evident' or invisible to others. Chronic fatigue syndrome and back pain, for example, are not apparent conditions. Other disabilities might remain hidden because they are episodic. Epilepsy is one example. Similarly, environmental sensitivities can flare up from one day to the next, resulting in significant impairment to a person's health and capacity to function, while at other times, this disability may be entirely non-evident. Sometimes, a person's disability may be mislabeled and misunderstood.
>
> **Example** (word is in bold in original text): People who are deaf, deafened or hard of hearing are often misperceived as having mental health disabilities, even where this is not the case.
>
> Other disabilities may become apparent based on the nature of the interaction, such as when there is a need for oral communication with a person who has hearing loss or a speech and language disability, or there is a need for written communication with someone who has a learning disability. A disability might reveal itself over time through extended interaction.

> It might only become known when a disability accommodation is requested or, simply, the disability might remain 'non-evident' because the individual chooses not to divulge it for personal reasons.
>
> **Example** (word is in bold in original text): A woman with breast cancer chose not to tell her employer of her condition until she was preparing to start treatment and required flexibility in her work schedule to attend medical appointments (OHRC, 2016, p. 12).

In summary, persons with disabilities have historically been subject to abuse and discrimination. Disability in the broadest sense encompasses a wide range of impairments, functional limitations, and barriers to participation, in community life (WHO, 2001). The United Nations adopted the Convention on the Rights of Persons with Disabilities and the United States and Canada have developed definitions and enacted legislation to protect their basic rights and freedoms. Definitions of disability today include non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities. This is more reflective of the majority of persons with disabilities across the globe. It is important to remember that persons with visible illness/disabilities may also have a myriad of non-visible illness/disabilities that they may or may not choose to disclose (Stone, 2005). In the next chapter I will briefly discuss the dominant models of disability. In so far as these paradigms are pervasive in society and impact our clients' identity, sense of self, and behavior as well as our own practices, it is incumbent upon counselors and psychotherapists to familiarize ourselves with their fundamental tenets. I will then delve more in-depth into the specific and unique experience of those with non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities in terms of mental health, identity, existential & spiritual issues.

Chapter 2: Dominant Models of Disability and the Relevance to Persons with Non-Visible Illness/Disabilities and Progressive and/or Acquired Non- Visible Illness/Disabilities

Disability Studies is an interdisciplinary field of study which tries to understand and improve the situation of those with disabilities through research and scholarship (Ferguson & Nusbaum, 2012; Heyer, 2007). Disability theorists point out that dominant models of disability permeate society and have an impact on those with disabilities, their identity, sense of self and behavior (Ashby, 2011; Bassler, 2014; Cornish et al., 2008; Davis, 2005; Shakespeare, 1996, 2005; Shakespeare & Watson, 2001; Stone, 1995, Smart & Smart, 2006; Stuntzner & Hartley, 2014; Valeras, 2010). In as much as counsellors and psychotherapists have enculturated these models, our practices may be profoundly affected which in turn impacts our clients (Cornish et al., 2008; Johnson, 2011; Smart & Smart, 2006; Stuntzner & Hartley, 2014; Valeras, 2010). There is no agreement in the literature as to an exact taxonomy of disability theories, however, certain models of disability are prevalent (Gilson & DePoy, 2002). Dominant disability study paradigms include the medical model and social model, and these can be diametrically opposed in terms of defining the locus of the problem as well as potential solutions (Davis, 2005; Heyer, 2007; Shakespeare, 1996, 2005; Shakespeare & Watson, 2001). Another predominant model of disability is the post-structural model which brings personal experience of impairment back into perspective (Shakespeare, 1996; Zola, 1993). There are other important paradigms in disability studies such as social constructionism, which seeks to situate the "problem" of disability within the problematical norms of mainstream society, and critical disability studies which critically examines the inherent "truths" as advocated by the discipline and seeks to move away from binary understandings – "social v medical model, British v American disability studies, disability v impairment" (Meekosha & Shuttleworth, 2009, p. 50; Shildrick, 2012; Vehmas & Watson, 2014). Crip theory

is a critical discourse which places disability as a subset of the queer narrative, but critics see it as fracturing of the community as it privileges visibly disabled bodies (Bone, 2017). Here I will focus on the medical, social, and post-structural models of disability as there has been much written about their pervasiveness in society and the impact on our clients (Ashby, 2011; Bassler, 2014; Davis, 2005; Shakespeare, 1996, 2005; Shakespeare & Watson, 2001; Shildrick, 2012; Stone, 1995; Söder, 2009; Valeras, 2010). I will briefly describe these dominant models of disability in the following paragraphs and then the relevance to those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities as well as our counselling and psychotherapy practices (Ashby, 2011; Bassler, 2014; Davis, 2005; Shakespeare, 1996, 2005; Shakespeare & Watson, 2001; Shildrick, 2012; Stone, 1995; Valeras, 2010).

The medical model of disability postulates biological determinism, where disability is a long term or permanent medical problem situated within the individual, be it physical, behavioral, psychological, cognitive, or sensory (Bassler, 2014; Davis, 2005; Evans, 2017; Gilson & DePoy, 2002; Hosking, 2008; Hughes & Patterson, 1997; Shakespeare, 1996, 2005; Stone, 1995; Valeras, 2010). This standpoint is premised on the idea of the "perfectly flawless body," that there are certain norms that persons should meet in terms of their abilities and that people who do not fall within these norms should be fixed (Bassler, 2014; Davis, 2005; Ellis-Hill et al., 2008; Heyer, 2007; Hosking, 2008; Shakespeare, 1996; Stone, 1995, p. 415; Valeras, 2010). Implicit in this idea is that disease may be considered a failure of will (Davis, 2005; Vickers, 2000). In this view, persons with disabilities may be viewed as "not whole" or "fundamentally flawed" (Block & West, 2013, p. 782). The persons to fix these flaws are medical doctors and rehabilitation professionals, who are practiced in adaptive, curative, or restorative services (Bassler, 2014; Ellis-Hill et al., 2008; Gilson & DePoy, 2002; Heyer, 2007; Shakespeare, 1996; Valeras, 2010). Persons with

disabilities who adhere to this perspective may believe that there is little that they can do to overcome their difficulties and are more inclined to rely on medications and "expert" opinions (Davis, 2005; Ellis-Hill et al., 2008; Shakespeare, 1996; Shakespeare & Watson, 2001).

The social model of disability, conversely, views disability as a problem within society (Evans, 2017; Meekosha & Shuttleworth, 2009; Shakespeare, 1996, 20005; Shakespeare & Watson, 2001; Stone, 1995; Valeras, 2010). From this perspective, persons with disabilities are limited from reaching their potential because of negative societal attitudes and exclusionary policies and practices which create oppressive barriers (Meekosha & Shuttleworth, 2009; Shakespeare, 1996, 2005; Valeras, 2010). Negative societal attitudes include the idea that persons with disabilities are less than their able-bodied counterparts (Davis, 2005; Stone, 2005, Valeras, 2010). The prevalence of these attitudes permeates society and workplaces so that individuals may choose to remain silent about their disability and accommodation requirements (Bassler, 2014; Davis, 2005; Gouvier & Coon, 2002; Heyer, 2007; Lingson, 2008; Mueller et al., 2020; Shakespeare, 1996; Stone, 1995; Valeras, 2009, 2010). Exclusionary policies and practices include inadequate and hard to access academic and work accommodations and inaccessible environments which limit access to participation (Hughes & Patterson, 1997). This often leads to economic, political, and societal inequities for those with disabilities (Bassler, 2009; Lingsom, 2008; Goodley, 2013). According to the social model, impairments are part of the human experience and disability is a consequence of social systems that create disabling conditions. The focus of intervention changes from the individual and "expert" voices to social systems, including environments and institutions (Heyer, 2007). From this view, the disability community should embrace their disability identity, make the word disability culturally acceptable and fight with others against systemic oppression (Bogart, 2014; Davis, 2005; Ferguson & Nusbaum, 2012;

Goodley, 2013; Heyer, 2007; Shakespeare, 1996, 2005; Shakespeare & Watson, 2001; Shildrick, 2012; Stone, 1995; Valeras, 2010; Zola, 1993). Persons with disabilities who abide by this paradigm may have more of a sense of self efficacy and self-worth than those who have faith in the disempowering medical model, so long as they identify as disabled or fall within the dominant visibly disabled group (Bogart, 2014; Bone, 2017; Davis, 2005; Heyer, 2007; Shakespeare, 1996, 2005; Shakespeare & Watson, 2001; Stone, 1995; Valeras, 2010).

The post-structural model of disability seeks to both acknowledge disability as social oppression and honour individual experiences of impairment (Hughes & Patterson, 1997; Shakespeare, 1996, 2005; Söder, 2009). According to this paradigm, the social model of disability has sought to right the wrongs of the medical model; however, both can be essentialist and speak about a reality that is not reflective of nuanced individual difference (Barnes, 2012; Evans, 2017; Goodley, 2013; Hoppe, 2013; Meekosha & Shuttleworth, 2009; Shakespeare, 1996; Shildrick, 2012; Söder, 2009; Vehmas & Watson, 2014). This is particularly true of the social oppression model, according to Shakespeare (1996). Shakespeare (2005) highlights the problem of speaking about disabled people as a category, "given the differences between types and causes of impairments, and the interrelation of impairment and disability with other social divisions and identities" (p. 146). The post-structural model of disability acknowledges that social barriers are a major ill for all that struggle with impairment but is wary of painting all with disabilities with the same brush. Persons with disabilities who abide by this paradigm would want us to listen carefully to their individual stories (Evans, 2017; Goodley, 2013; Kramer-Golinkoff, 2014; Meekosha & Shuttleworth, 2009; Nochi, 1998; Shakespeare, 1996; Söder, 2009; Vehmas & Watson, 2014).

The relevance of the dominant models of disability to those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities is that most

individuals do not find an explanation for their experience in either the medical or social disability paradigms (Meekosha & Shuttleworth, 2009; Valeras, 2010). The post-structural model is a better fit in that it sheds light on the nature of human beings as intersectional, nuanced and fluid (Shakespeare, 1996; Meekosha and Shuttleworth, 2009; Shildrick, 2012; Vehmas & Watson, 2014; Valeras, 2010). Most find the idea that they are fundamentally flawed, as per the medical model, offensive. At the same time the social model of disability, in focusing on disability rights, fails to address persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disability who do not always consider disability as their "sole and significant identity" (Bone, 2017; Shakespeare, 1996, p. 109; Valeras, 2010). Many with non-visible illness/disabilities choose to conceal their impairment for a multitude of reasons, including maintaining an able-bodied appearance, and circumventing the problems impairment might bring (Davis, 2005; Lingsom, 2008; Meekosha & Shuttleworth, 2009; Mueller et al., 2020; Nochi, 1998; Nutting & Amos, 2020; Valeras, 2009, 2010). Whilst some may take exception to the buying in to societal prescriptions for conformity, that those with non-visible illness/disabilities choose to identify as able-bodied is up to them and needs to be respected (Mueller et al., 2020; Vehmas & Watson, 2014). Those with non-visible illness/disabilities may be up against other barriers in the workplace such as racial prejudice and prefer to choose this battle over that for accommodations. Neither embracing the idea that they are personally flawed nor solely disabled, persons with non-visible illness/disabilities would prefer to be recognized for the unique and nuanced qualities of every one of their experiences (Bassler, 2014; Bone, 2017; Davis, 2005; Ferguson & Nusbaum, 2012; Goodley, 2013; Kramer-Golinkoff, 2014; Lingsom, 2008; Nochi, 1998; Shakespeare, 1996; Stone, 1995, 2005; Taylor, 2005; Valeras, 2009, 2010; Zola, 1993).

It is incumbent upon counsellors and psychotherapists to familiarize ourselves with the foremost disability paradigms to better understand clients' experience and to reflect upon where we situate ourselves in our practices (Valeras, 2010; Olkin, 2007). For example, are clients perceiving disability as a problem within themselves, as per the medical model, which requires remediation from expert professionals? If so, does this culminate in "disabled passivity," the tendency to completely defer important health care decisions to their expert team, negatively impacting their self-esteem and sense of self-efficacy (Shakespeare, 1996; Zola, 1993, p. 170)? Are counsellors and psychotherapists in agreement with this paradigm and so believe that we ultimately know what's best for our clients? Conversely, do our clients believe that societal barriers are to blame for their difficulties, as per the social model, and therefore that embracing a collective disability identity is imperative to fight for legislative changes? Does this positively impact their sense of self or result in them feeling marginalized, particularly if they do not identify as disabled (Evans, 2017; Shakespeare & Watson, 2001; Valeras, 2010)? Are we as counsellors and psychotherapists in agreement with this paradigm and therefore assist our clients in advocating for social change? Do we find ourselves closed off to clients that do not identify as disabled and want to talk about their personal experience of pain? Finally, do our clients understand their disability as a consequence of both societal oppressions/barriers and individual experiences of impairment, as per the post-structural model, thereby asking that we understand the totality of their situation (Davis, 2005; Shakespeare, 1996; Shakespeare & Watson, 2001)? Are we as counsellors and psychotherapists in agreement with this paradigm and therefore strive to understand the unique quality of their experience? Do we ensure that we are working collaboratively with our clients to co-construct goals for therapy and evaluate progress (Duchan, 2004)? It behooves us as counsellors

and psychotherapists to pay attention to our own beliefs and that of our clients regarding disability paradigms to gain a better understanding and intentionality as we help.

Chapter 3: Persons with Non-Visible Illness/Disabilities and Progressive and/or Acquired Non-Visible Illness/Disabilities: Mental Health, Identity, Existential and Spiritual Issues

> But they don't see that the crack is always there, and it always will be. It's always gonna be there, and it's always gonna be invisible, but it's felt. ... I recently heard that, um—in talking about race—that some people wake up every day, and they—have this thing that they have on their shoulders— before they go into their day, and I just wanted to scream, "I get it." But it doesn't feel socially acceptable for me to say that. When we talk about inequity I'm not included. This disability is not at the same level, and especially because it's invisible (Molly, a person with a non-visible illness/disability) (Evans, 2017, para. 56).

In addition to the rendering of persons with non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities in the Americans with Disabilities Act (ADA), the *Ontario Human Rights Code* (HRC) and the dominant models of disability, their experience has been further expounded by academics and researchers in the field of disability studies in the areas of mental health, identity, and existential and spiritual issues. Bayliss, Edwards, Steiner, and Main (2008) point out that persons with non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities have unique qualities such as fluctuating symptoms that need to be better appreciated by health care professionals. This is true for persons with CF who may have intermittent periods of health and exacerbations sometimes resulting in hospitalizations (Mueller et al., 2020). Understanding non-apparent and fluctuating symptoms plus the capriciousness of their abilities is complex work. For this reason, those living with non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities often have a profound sense of

isolation as they as well as family, friends and helping professionals attempt to make sense of their experience (Bassler, 2009, 2014; Bayliss et al., 2008; Davis, 2005; Dickson et al., 2007; Lingsom, 2008; Livneh & Antonak, 2005; Maxam & Henderson, 2013; NARIC; Olney & Brockelman, 2003; Patterson & Staton, 2009; Taylor, 2005; Valeras, 2009, 2010). Many with progressive and acquired non-visible illness/disabilities may also struggle to find their way in a world where they no longer feel valued nor find meaning (Davis, 2005; Graham et al., 2008; Stone, 1995, 2005; Shakespeare, 1996). In this chapter I shall outline the unique mental health, identity, existential and spiritual issues of persons with non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities as outlined in the literature.

3.1 Persons with Non-Visible Illness/Disabilities and Progressive and/or Acquired Non-Visible Illness/Disabilities: Mental Health Issues

In terms of the mental health issues of those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities, they face physical and social barriers, for example intransigent workplace schedules, and dominant ideologies about perfectly able bodies, that impact their sense of well-being (Bassler, 2014; Davis, 2005; Lingson, 2008; Mueller et al., 2020; Shakespeare, 1996; Stone, 1995; Valeras, 2009, 2010; Vickers, 2000). Many workplaces require long hours with allotted breaks, however, persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities may be unable to work for long blocks of time (Davis, 2005). Workplaces are beginning to make accommodations available to persons with non-visible illness/disabilities, however, these changes are gradual and require justification on the part of persons with impairments (Davis, 2005; Lingsom, 2008; Mueller et al., 2020; Valeras, 2009, 2010). The process of asking for accommodations has multiple dimensions, and is both demanding and stressful (Bassler, 2009;

Heyer, 2007; Lingsom, 2008; Valeras, 2009, 2010). Dominant ideologies in western culture promulgate "the myth of bodily perfection," which results in the pressure to appear "normal" (Davis, 2005; Mueller et al., 2020; Stone, 1995, p.413; Valeras, 2010).

> The prefix dis means absence of, opposite of, or deprived of (American Heritage Dictionary, 2000). Putting the word back together leads to the conclusion that a person with a disability has absence of ability, encompasses the opposite of ability, or is deprived of ability (Valeras, 2010, p.10).

To adhere to "the myth of bodily perfection" many will suffer in silence regarding their impairment(s) (Bassler, 2009; Lingsom, 2008; Mueller et al., 2020; Stone, 1995, p. 413, 2005; Valeras, 2010; Vickers, 2000). The following are chief mental health issues that persons with non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities face: living in "a permanent state of conflict"; the dilemma of concealment vs disclosure; and the reality that many loved ones as well as helping professionals are hard pressed to believe them (Davis, 2005, p. 189; Macdonald et al., 2019; Mueller et al., 2020). I shall elaborate on these ideas in the following paragraphs.

Living in a body that appears able but belies the truth of their underlying impairment, persons with non-visible illness/disabilities and progressive and acquired non-visible illness/disabilities may experience a "permanent state of conflict" between one's perception of oneself and the perception of others (Davis, 2005, p.189; Sturge-Jacobs, 2002; Valeras, 2010). "Invisible impairments constitute a 'category crisis' as they combine able bodied appearance with impairment" (Lingsom, 2008, p. 2). Where persons with visible disabilities are "discredited" (because they overtly fall short of ideologies that honour the perfect body) those with non-visible disabilities are "discreditable" in that the reality of their impairments may at any time surface

(Davis, 2005; Gouvier & Coon, 2002; Lingsom, 2008, p. 4; Meekosha & Shuttleworth, 2009; Shakespeare & Watson, 2001; Stone, 1995; Vickers, 2000). Should their impairments surface persons with non-visible illness/disabilities and progressive and /or acquired non-visible illness/disabilities may fear being objectified as "the alien Other" thereby being devalued, tuned out or worse (Berlin et al., 2005; Davis, 2005; Fitzgerald & Patterson, 1995; Mueller et al., 2020; Stone, 1995, p. 421; Valeras, 2009, 2010). For this reason, they may avoid attending to their bodies or situations where they may be found out (Borschuk et al., 2016; Oliver et al., 2014; Quittner et al., 2016; Modi et al., 2010; Smith et al., 2016; Stone, 2005; Valeras, 2009, 2010). This may result in poorer health and cutting oneself off from the satisfaction of authentic relationships leading to feelings of isolation (Davis, 2005; Fitzgerald & Patterson, 1995; Lingsom, 2008; Valeras, 2009, 2010). As example, youth with CF may have delayed growth and may be frustrated if they are being treated younger than their chronological age. They may be embarrassed about other symptoms and overt treatments and anxious about people finding out lest they experience bullying and rejection (Berlin et al., 2005; Mueller et al., 2020). The result of living in a "permanent state of conflict" has negative psychological consequences, for example, social isolation, and may lead to poorer physical health outcomes when treatments are avoided (Davis, 2005, p. 189; Fitzgerald & Patterson, 1995; Lingsom, 2008; Mueller et al., 2020; Pachankis, 2007; Ragins, 2008; Valeras, 2009, 2010).

Persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities face the dilemma of concealment vs disclosure in all areas of life, and particularly in the realms of academia and work (Bassler, 2009; Lingsom, 2008; Macdonald et al., 2019; Nutting & Amos, 2020; Valeras, 2009, 2010; Mueller et al., 2020). In these settings, they may feel torn between their desire to fit in and the need for accommodations (Bassler, 2009;

Valeras, 2009, 2010; Mueller et al., 2020). Bassler (2009) surveyed and interviewed 25 scholars within Academia with various forms of non-visible illness/disabilities - invisible auto-immune diseases and mental illnesses - and found the following: should persons with non-visible illness/disabilities conceal their impairment(s) they are subject to the same norms and expectations as their non-disabled counterparts without the necessary accommodations to succeed. The choice of concealment may lead to their work being scrutinized and they may face criticism when they do not perform up to normative standards. The effects of their disability may be misconstrued as professional incompetence (Bassler, 2009). Alternatively, should they disclose their impairment(s) they may be up against the judgement of others and potentially missing out on tenure positions and new opportunities (Bassler, 2009). Heyer (2007) introduces the idea of stigma in asking for workplace accommodations. Stigmas are individual characteristics that are devalued or viewed as personal flaws, and may be context specific (Heyers, 2007; Ragins, 2008; Zola, 1993). Should persons with non-visible illness/disabilities ask for accommodations this might "carry the stigma of special" and seem to others as unfair (Heyer, 2007, p. 271). Health-related stigma is a social process in which negative judgement based on a health condition begets rejection, blame or devaluation (Oliver et al., 2014). This sentiment is evident in the statement of one participant in the study by Macdonald et al. (2019), "I don't want to be looked at and looked down on or felt sorry for. That's my thing with CF" (p. 949). In one study assessing stigma in patients with CF, a CF-specific Stigma Scale was developed and found that symptoms such as coughing negatively affected public reactions and misconceptions (Pakhale et al., 2014). Findings showed that "quality of life is significantly impacted by patients' experienced symptoms as a result of their experienced stigma" (Pakhale et al., 2014, p. 5). It follows that many with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities, such as CF, choose to conceal rather

than disclose their impairment(s) for fear of stigmatization (Bassler, 2009; Borschuk et al., 2016; Macdonald et al., 2019; Modi et al., 2010; Nutting & Amos, 2020; Oliver et al., 2014; Pakhale et al., 2014; Quittner et al., 2016; Smith et al., 2016). Lingsom (2008) and Davis (2005) as well as Evans (2017) do see an adaptive and empowering quality to concealment, but all concede that this has time limited advantage. For example, concealment may be preferable when someone has a progressive and/or acquired non-visible illness/disability and requires time to adjust to and integrate a new sense of self. Lingsom (2008) speaks about both the concepts of passing and concealment:

> Passing may be appreciated as moments of forgetfulness when impairment and disability fade into the background. These moments provide a restful 'time out' for all. People with recently acquired impairments may seem to be their 'old selves.' Concealment may be an integral dimension of cognitive self-therapy which has a positive focus on health, capability, and opportunity (Lingsom, 2008, p. 5).

A common passing strategy may be to judiciously select where and when to pass as normal, for example at work (Lingsom, 2008). This may adversely affect family and friends where energy has been spent hiding "impairment effects" at work, thereby leaving little energy left for one's relationships (Lingsom, 2008, p.7). Individuals may disclose their impairments differently across life domains and this may lead to disclosure disconnects (Ragins, 2008). The decision to disclose one's impairment may include assessing risks, benefits, and the perceived safety of one's environment (Ragins, 2008). "Un/covering" one's impairment may be an ideal process whereby one slowly reveals their difficulties when the context is safe, for example at first with a trusted friend (Evans, 2017, para. 1). Preventative disclosure in those with non-visible illness/disabilities and progressive non-visible illness/disabilities, such as CF, may offset misattributions of their

illness, and prevent negative social consequences (Berlin et al., 2005). "Goffman (1963: 125) regarded voluntary disclosure as the final, mature, well-adjusted phase in the 'moral career' of the stigmatized person" (Lingsom, 2008, p. 9). According to Lingsom (2008) there are many motives for disclosure, including legitimately reducing demands and pressures on oneself as well as personal integrity and cohesion. Most authors agree that disclosure is the healthiest option for those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities as this allows them to embody their experience and may lead to a more whole, congruent, and integrated sense of self (Bassler, 2009, 2014; Davis, 2005; Evans, 2017; Lingson, 2008; Mueller et al., 2020; Ragins, 2008; Shakespeare, 1996; Söderberg et al., 1999; Stone, 1995; Valeras, 2009, 2010). In one study, disclosure was assessed using the Cystic Fibrosis Disclosure Questionnaire (Borschuk et al., 2016). Findings showed that disclosure can have a positive impact on independence, improve treatment adherence and psychosocial outcomes (Borschuk et al., 2016; Quittner et al., 2016). To foster disclosure a radical shift is required in academia, in all work environments and in society where there is an openness to difference and more malleable responses to individual needs (Bassler, 2009). A more inclusive environment would benefit those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities and every one of us (Davis, 2005).

Persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities may be met with disbelief by extended family members and friends, colleagues as well as medical and helping professionals (Balcazar et al., 2004; Bassler, 2009; Block & West, 2013; Davis, 2005; Dickson et al., 2007; Evans, 2017; Gordon et al., 1998; Gray & Fossey, 2003; Hareide et al., 2011; Juuso et al., 2011; Lingsom, 2008; Olney & Brockelman, 2003; Pinxsterhuis et al., 2015; Sharma et al., 2020; Shaw, 2012; Söderberg et al., 1999; Stone, 1995; Taylor, 2005;

Valeras, 2009, 2010; Vickers, 2000; Warnecke, 2017). In that the dominant idea about disability is that it is visible, the social narrative of those with non-visible illness/disabilities is one of "disbelief and suspicion" (Lingsom, 2008, p. 9). Since their disabilities are less obvious than those with visible disabilities their struggles may be perceived as less real or severe (Dickson et al., 2007; Lingsom, 2008; Söderberg et al., 1999; Sturge-Jacobs, 2002; Valeras, 2009, 2010). Valeras (2009) interviewed four women, aged 21 to 46, with hidden disabilities – juvenile rheumatoid arthritis, epilepsy, mitochondrial myopathy, and celiac disease. During the course of the interviews, a common theme arose: family, friends and service providers did not believe them because their impairments were non-visible, and their acute symptoms were variable (Valeras, 2009). Perceived skeptical attitudes from support systems has the consequence of minimizing one's own experience (Valeras, 2009). Health care professionals have been shown to react more favourably to persons with visible illness/disabilities than those with non-visible illness/disabilities. When faced with persons with non-visible illness/disabilities they may react with disbelief, lack knowledge about how the impairment presents itself, lack responsiveness and adequate treatment planning and referrals (Dickson et al., 2007; Hareide et al., 2010; Sturge-Jacobs, 2002; Valeras, 2009; Warnecke, 2017). Whilst CF is a congenital largely non-visible illness/disability, many individuals have been diagnosed as adults and until then struggled with a healthcare system that did not believe them and misdiagnosed their symptoms thereby delaying lifesaving treatments (Sharma et al., 2020). In one study addressing patients' experiences of being diagnosed in adulthood, four themes emerged, including: "No, you can't possibly have CF" (Sharma et al., 2020). The diagnosis of CF is not consistent across countries, for example, CF was thought to be non-existent in India, and disbelief may come in many forms including inattention to matters of women's sexual health despite new treatments which positively impact fertility

(Heltshe et al., 2017; Langawai et al., 2020). Women with CF have poorer healthcare outcomes and specialists are still hypothesizing as to why (Langawi et al., 2020). There is a call for updated knowledge, greater awareness and understanding of women's physical and mental health overall and with regards to their sexual health (Langawi et al., 2020). Many authors refer to the stress that those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities are under when they have to prove themselves to others in order to get accommodations and treatment and that this can have an impact on their immune system, exacerbate their problems and cause them to feel shame and fear when asking for help (Bassler, 2009; Davis, 2005; Valeras, 2009, 2010). They may internalize the disbelief of others and question their own legitimacy or deny their illness/disability, which might have consequences for their self-concept (Dickson et al., 2007; Fitzgerald & Patterson, 1995; Graham et al., 2008; Juuso et al., 2011; Shaw, 2012; Söderberg et al., 1999; Stone, 2005; Valeras, 2009, 2010). Persons with non-visible impairments perceive others as not understanding the nuance of their experience and, when loved ones and helping professionals do not believe them, this can lead to a sense of despair (Bassler, 2009; Davis, 2005; Dickson et al., 2007; Lingson, 2008; Söderberg et al., 1999; Stone, 1995; Valeras, 2009, 2010). A human paradigm is needed that is more inclusive and accords weight to the experience of persons with non-visible illness/disabilities (Davis, 2005). Once persons with non-visible illness/disabilities and/or acquired non-visible illness/disabilities are believed they can focus on the business of living instead of the fight for human dignity (Söderberg et al., 1999).

In terms of the mental health issues specifically of those with progressive and/or acquired non-visible illness/disabilities, they are faced with loss and grief, the uncertainty and unpredictability of their impairment, and must somehow adjust to a new reality (Dezutter et al.,

2015; Gray & Fossey, 20013; Juuso et al., 2011; Livneh & Antonak, 2005; Lorenz, 2010; Niemeier, 2008; Psarra & Kleftaras, 2013). Among the losses may be their pre-existent functioning, identity, independence, socioeconomic level, relationships, and familial, social, and vocational roles (Gray & Fossey, 2003; Livneh & Antonak, 2005; Lorenz, 2010; Mueller et al., 2020; Niemeier, 2008; Psarra & Kleftaras, 2013; Varilek & Isaacson, 2020). This may lead to a psychosocial crisis in their lives and a period of adaptation (Hjelm et al., 2020; Livneh & Antonak, 2005; Lorenz, 2010; Mueller et al., 2020; Psarra & Kleftaras, 2013; Varilek & Isaacson, 2020). Having a progressive and/or acquired non-visible illness/disability may have a significant impact on both an individual's intrapersonal and interpersonal functioning and may lead to depression and anxiety (Dezutter et al., 2015; Livneh & Antonak, 2005; Psarra & Kleftaras, 2013). Gender may significantly impact grief symptoms, with women twice as likely to experience depression (Niemeier, 2008). Self-acceptance may be a challenge as impairments are not apparent to others (Folzer, 2001). Lung disease is often the main manifestation of CF; however, many individuals develop CFRD which requires lifestyle modifications, additional treatments, and care management difficulties that may trigger sadness and fear (Hjeln et al., 2020). Hjelm et al. (2020) showed a significant association between CFRD and depression in a cohort of adult patients. CF is a progressive largely non-visible illness/disability, and there are many adjustments and losses including "death of a job," "death of a relationship," "death of lung function" and "death of independence" (Varilek & Isaacson, 2020, pp. 3558-3559).

When working with individuals with CID (chronic illness and disability), counsellors are commonly called to draw on their expertise in the areas of a) stress, crisis, and coping with loss and grief; b) the impact of traumatic events on self-concept, body image, and quality of life; and c) the effects of disability-linked factors (e.g. uncertainty, unpredictability) and

> societal reactions (stigma, prejudice) on psychosocial adaptation to CID (Livneh & Antonak, 2005, p. 18).

As counsellors and psychotherapists, it is important to understand that our clients with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities may be troubled by their impairments but are reticent to fully own their pain and disclose their difficulties due to societal pressures to conform (Gordon et al., 1998; Stone, 1995). This may have a negative impact on their mental health by alienating them from their bodies. It befits us to reflect upon our practices, particularly in relation to our own ideas about disability, and integrate the idea that impairment is a continuum and part of the diversity of human experience (Bassler, 2009, 2014; Davis, 2005; Duchan, 2004; Ferguson & Nusbaum, 2012; Gilson & Depoy, 2002; Hirschmann, 2012; Shakespeare, 2005; Shakespeare & Watson, 2001; Shildrick, 2012; Stone, 1995; Valeras, 2009, 2010; Zola, 1993). Being that all of us are aging and all bodies do break down it is most likely that we will all struggle at some point with a non-visible illness/disability (Bassler, 2009, 2014; Davis, 2005; Feely, 2016; Valeras, 2009, 2010; Zola, 1993). To embrace those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities therefore would be to embrace all of us, our own vulnerability and humanity (Davis, 2005; Feely, 2016; Ellis-Hill et al., 2008). Once we reimagine that "difference is what we all have in common" we are better positioned to believe and accept our clients, which will help them to integrate and process their experience including grief and embrace a valued sense of self (Bassler, 2014, p. 5; Feely, 2016). As Söderberg, Lundman, and Norberg (1999) have found in their study of women's experiences living with the chronic pain condition, Fibromyalgia, "belief brings relief" (p. 584).

3.2 Persons with Non-Visible Illness/Disabilities and Progressive and/or Acquired Non-Visible Illness/Disabilities: Identity Issues

> CF can take a toll on your mental health, but I always try to remember that there is so much more to who I am than just having cystic fibrosis (Nutting & Amos, 2020, p. 170).

In terms of the identity issues of those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities, a problem arises in that many do not identify as disabled or are not accepted by the disability community that may privilege those with visible disabilities, thereby not benefiting from these affiliations (Bogart, 2014; Bone, 2017; Evans, 2017; Heyer, 2007; Nochi, 1998; Shakespeare, 1996; Taylor, 2005; Valeras, 2010). The social model has worked to turn around the negative self-identity of those with disabilities who had bought into the medical model's unconstructive characterizations of them (Shakespeare, 1996, 2005; Shakespeare & Watson, 2001; Valeras, 2010). According to the social paradigm, "assimilation is the name of the game" and the idea has been to collectively challenge social and cultural contexts that are at the root of inequitable practices (Shakespeare, 1996, p. 99; Valeras, 2010). "Coming out" is preferable to self-blame (Shakespeare, 1996, p. 100). One of the dangers of integration, however, is that individual identities and diversity of experience disappears (Bone, 2017; Hosking, 2008). For example, "some impairments are static, others are episodic or degenerative. Some mainly affect appearance, others restrict functioning" (Shakespeare & Watson, 2001, p. 15). Further, what of those who do not identify as disabled but prefer to identify judiciously given the right context and where there is a need to do so, for example, in the case of vying for accommodations? What of those who have multiple identities and "simultaneous oppression" and make identity choices, for example, in the instance of race (Shakespeare, 1996, p. 109; Gilson & Depoy, 2002)? What about those whose "hybrid intersectionalities" or "multidimensionality" means that they

experience privilege in some areas but subordination in others (Hosking, 2008, p. 10)? For example, a male who is disabled may experience gender privilege but disability inferiority (Hosking, 2008). When one adds disability into the mix, which membership(s) or identities are attached to and are of primary import? Which identities are static or fluid in alignment with context and personal and collective decision making? Making assumptions regarding the identity of those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities is to obfuscate their reality and the meanings that they attribute to their world, which may result in not feeling seen or heard (Valeras, 2010).

Gilson and Depoy (2002), in their study with persons of diverse birth-based and acquired disabilities, sought to better understand disability cultural identity and the data showed that disability identity was "a personal, individual characteristic that varied in its primacy, importance, and meaning to each informant" (p. 7). Valeras (2009, 2010) and others have pointed to the fact that many with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities do not identify as disabled for a multitude of reasons (Bassler, 2014; Bone, 2017; Davis, 2005; Evans, 2017; Gordon et al.,1998; Lingson, 2008; Meekosha & Shuttleworth, 2009; Nochi, 1998; Ragins, 2008; Shakespeare, 1996; Stone, 1995; Taylor, 2005). In the first place, ableist ideas about disability give persons pause about owning an identity that has been characterized as less than (Bassler, 2014; Bone, 2017; Gordon et al.,1998; Gouvier & Coon, 2002; Davis, 2005; Lingson, 2008; Meekosha & Shuttleworth, 2009; Nochi, 1998; Ragins, 2008; Shakespeare, 1996; Shakespeare & Watson, 2001; Stone, 1995; Valeras, 2009, 2010; Vickers, 2000). As well, many with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities see their impairments as non-static and therefore find the disability moniker totalizing and not descriptive of their experience (Evans, 2017; Gordon et al.,1998;

Meekosha & Shuttleworth, 2009; Taylor, 2005; Valeras, 2010). Persons with non-visible illness/disabilities may also want to own their disability as only a part of their identity, depending on time and situational context (Evans, 2017; Heyer, 2007; Lingsom, 2008; Valeras, 2010). After interviewing participants, all of whom had been living with a hidden physical disability, Valeras (2010) found that persons with non-visible illness/disabilities often identify as bi-abled in that they sometimes can "pass" for able bodied and sometimes they cannot. The binary identity structure inherent in disability theory – "either/or, disabled/nondisabled" – did not fit (Valeras, 2010, p.13). Instead, persons in her study perceived disability as a porous category, did not always identify as disabled and preferred that their flexible identities not be "put in a box" (Valeras, 2010, p.13). "Their stories revolt against the pressure our society upholds to dichotomize, segregate, and place people into clear-cut categories, and reveal the multiplicity and malleability of identity" (Valeras, 2010, p. 2). Many in Valeras' study (2010) expressed that their identities fall more readily on the continuum between the non-disabled and disabled worlds.

When acquiring a non-visible illness/disability, ableist ideas about disability being inferior have been ingrained by adolescence and may result in persons not accepting oneself as disabled (Gordon et al.,1998; Lingsom, 2008; Valeras, 2010). Persons with acquired impairments may "fluctuate between pre and post impairment identities" allowing them to gradually integrate a new sense of self (Lingsom, 2008, p. 5). Fitzgerald and Paterson (1995), in their study of persons with progressive and/or acquired non-visible illness/disabilities, temporomandibular joint disorder (TMJ) and multiple sclerosis (MS), found that persons in their study struggled to maintain a valued identity and sense of self. Many spoke in terms of, "I used to be" (Fitzgerald & Paterson, 1995, p. 19). Shakespeare's words on disability identity are particularly apt here:

> Disability is about stories, having the space to tell them, and an audience which will listen. It is about recognizing differences and isolating the significant attributes and experiences which constitute disability. Some we might choose to change, others to recuperate or celebrate. We may need to develop a nuanced attitude which incorporates ambivalence: towards our bodies, for example. Theory has a part to play in this process. But (metaphorically, if not physiologically), it all starts with having a voice. Foucault suggests, our task is to speak the truth about ourselves (Shakespeare, 1996, p. 111).

A word here on identity and disability language. There are those that believe that person first language is preferable, for example, "person with cystic fibrosis," and others who believe that putting the disability before the person, for example, "Deaf person," is a more fitting description. The difference is that person first advocates see the disabled moniker as totalizing and obfuscating of individual difference, and those that advocate for "disabled person" want those with disabilities to claim disability as their central identity (Evans, 2017; Gouvier & Coon, 2002; Heyer, 2007; Titchkowsky, 2001; Valeras, 2010; Vickers, 2000). Person first language aligns with the perceptions of many with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities who feel discomfort with the disability label (Gordon et al.,1998; Nochi, 1998; Valeras, 2009, 2010). This position has been aptly put by an individual suffering from rheumatoid arthritis in the study by Gordon, Feldman, and Crose (1998) on how women with chronic illness view their experiences:

> I say I have rheumatoid arthritis but I don't say that I am arthritic…arthritic carries for me a connotation of crippled or disabled…I don't think disabled is the right word…[If I say] I have arthritis; I'm still in charge of this. [If I say] I am arthritic; it suggests that it is more in control of me (p. 7).

"Disabled person" advocates align with the social model of disability and "suggest placing the disability before the person as a political statement to show that a disability is something that is 'done' to a person rather than something a person 'has'" (Heyer, 2007, p. 277). "Disabled person" monikers may also be validating if not totalizing and assist with adaptation, as in the following quote by a woman with MS:

> For a long time, I felt I was not disabled…I finally grew to accept that, hey, there is a problem here and I have got to deal with it. I can't pretend it doesn't exist because I'm not doing anybody good when I do that… (Gordon et al.,1998, p. 8).

To my knowledge, there are few studies which focus on CF and identity, however, one recent study sought to understand the illness centrality of adolescents with CF and the way that their illness impacts their identities through observing video narratives (Horky et al., 2017). Four major themes were identified related to illness centrality: CF is central, CF is compartmentalized, CF is integrated into self-image and CF is denied (Horky et al., 2017). Findings showed that older and sicker adolescents exhibited a higher percentage of CF related talk then their younger and healthier counterparts (Horky et al., 2017). Four themes emerged related to the role of CF in self-image and identity (the authors used these terms interchangeably): Valence, amount of control, difference/normalcy and acceptance/adaptation. Again, CF played a more noticeable role in the identities of older and sicker adolescents (Horky et al., 2017). Still, the authors point out that CF identity is not necessarily predictable and can be fluid. For example, some who were very sick denied their illness and others "did not have just one feeling about CF but felt differently at different times" (Horky et al., 2017, p. 1). The term disability was mentioned by one participant, in the theme of difference/normalcy. He stated, "…I think that's unfair for everyone and people take natural disabilities and think this person can't do that or this or none of that" (Horky et al.,

2017, p. 6). Amongst the authors' many clinical recommendations: demonstrate empathy and understanding that adolescents do not experience CF or identify with their illness in a singular way, so that we ensure they feel understood and supported (Horky et al., 2017).

"Understanding how an individual perceives the term disability and whether they think of their illness as a disability is essential information for counsellors" (Gordon et al.,1998, p. 9). For one thing, this might give us information on whether they feel empowered, disempowered or somewhere in between. Titchkowsky (2001) advocates for "an openness to a diversity of terms and expressions of disability" to be respectful of individual difference (p. 138). Given the above, it would seem beneficial to our clients with non-visible illness/disabilities that we make no assumptions about any realm of their identification and that we appreciate that they have many affiliations. It would seem good practice that we be open to the many voices of those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities, including how they identify and represent themselves in language.

3.3 Persons with Non-Visible Illness/Disabilities and Progressive and/or Acquired Non-Visible Illness/Disabilities: Existential & Spiritual Issues

Existentialism may be summarized as follows, "Man is an existential being whose life is more than logic and who must discover the meaning in existence" (Marseille & Messias, 2020, p. 394). As we move through life, concerns regarding existence may arise as well as questions regarding one's spirituality (the sense that there is something greater than myself) (Breitbart et al., 2004). Van Bruggen et al. (2017) outline existential concerns in five domains - death, meaninglessness, guilt, social isolation, and identity - and have developed the Existential Concerns Questionnaire (ECQ). Death anxiety, or anxiety provoked by the finiteness of life, is a common existential concern. Meaninglessness shall be discussed in detail in this chapter. Guilt is related to

not being able to fulfill one's expectations about life. Social isolation describes the experience of not feeling connected to others or not being able to share their perspective. Identity, in this context, relates to "not having full knowledge of oneself along with the inconsistencies in the experience of oneself and the world" (van Bruggen et al., 2017, p. 1693). The ECQ is based upon the conceptual work of Binswanger (1958), and Yalom (1980) amongst others (van Bruggen et al., 2017). For example, Yalom's existential givens include death, freedom, isolation and meaninglessness (Yalom, 1980). Yalom outlines three types of isolation: existential, intrapersonal, and interpersonal. Existential isolation is an inherent sense of disconnection between one's self and the world (van Bruggen et al., 2017). Other common existential themes include life and death, responsibility, accountability, loneliness, becoming, uncertainty, courage, anxiety, and fear (Marseille & Messias, 2020). People experience these themes in four domains of existence or ways of "being in the world:" the Umwelt (physical dimension), the Mitwelt (social dimension), the Eigenwelt (psychological or inner dimension), and the Uberwelt (spiritual dimension) ((Marseille & Messias, 2020, p. 394; van Deurzen, 2012).

In terms of the existential and spiritual issues of those with non-visible illness/disabilities, Lingsom (2008) highlights existential and aesthetic anxiety. Existential anxiety, in this instance, refers to fear of loss of autonomy due to impairment. Aesthetic anxiety refers to the fear of deviate appearance in a society that favours perfectly able bodies (Lingsom, 2008; Stone, 1995). When non-disabled persons experience existential and/or aesthetic anxiety they may distance themselves from those with disabilities, causing the latter to feel marginalized. "Fear for self" is fostered by the knowledge that they themselves may become disabled at any time, that the distinction between abled and dis/abled is provisional at best (Davis, 2005; Gouvier & Coon, 2002; Hirschmann, 2012; Ragins, 2008; Shildrick, 2012; Vickers, 2000, p. 143).

> An interaction with a person who has an invisible illness can be uncomfortable for the able-bodied person, since persons with invisible illnesses are a hallmark of what all persons will one day face, or may not be an unknown or undiscovered aspect of the invisible body: the breakdown of their bodies as a natural part of aging, the anxiety of possessing a disease or illness that silently occupies the body and is yet to manifest and affect the body (Bassler, 2014, p.4).

To ward off the existential and aesthetic anxieties of others as well as the stigmatization of being in a devalued group, persons with non-visible illness/disabilities may experience a failure to embody "one's true self" (Pachankis, 2007, p. 328). Persons with progressive and/or acquired non-visible illness/disabilities, such as CF, must integrate at some point being disabled, and may experience existential and aesthetic anxiety which can cause internal conflict and self-loathing (Pachankis, 2007; Varilek & Isaacson, 2020). The question may become, who am I now that I am no longer perfectly able (Fitzgerald & Paterson, 1995; Varilek & Isaacson, 2020)?

In a study regarding the existential and spiritual issues of those with CF, Trandel et al. (2019) evaluated the relationship between symptom burden and five existential needs representing existential distress: 1) fears about my CF getting worse; 2) learning to feel in control of your situation; 3) uncertainty about the future; 4) feelings about death and dying; and 5) concerns about the worries of those close to you. Results showed these perceived unmet existential needs were more prevalent in those with higher symptom burden. The authors therefore recommend that CF-specific palliative care programs be developed to provide psychological and spiritual support to those struggling with symptom burden and needing answers to these challenging concerns (Trandel et al., 2019).

Those with non-visible illness/disabilities may face existential and spiritual issues regarding meaning and purpose in life. Persons with progressive and/or acquired non-visible illness/disabilities once had highly functional lives and are now unable to engage with the world or perform as they once did (Carroll & Coetzer, 2011; Dezutter et al., 2015; Graham et al., 2008; Hjelm et al, 2020; Lorenz, 2010; Mueller et al., 2020; Niemeier, 2008; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Söderberg et al., 1999; Sturge-Jacobs, 2002). For example, persons with CF may develop more comorbidities as they age such as CFRD, which requires increasing management of symptoms and sometimes a transition to part time work (Hjelm et al, 2020; Mueller et al., 2020). Individuals in transition may feel isolated, and without a sense of meaning and purpose as old roles and abilities fade away. It may leave them asking the question, "why me?" (Block & West, 2013; Graham et al., 2008; Lorenz, 2010; Oliver, 1995; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Söderberg et al., 1999). In addition to the physical effects, those afflicted may be faced with what Yalom termed "the phenomenon of boundary experience" (Patterson & Staton, 2009, p. 142). They are forced to come to grips with fundamental elements of the human experience, existential givens such as death, freedom, isolation, and meaninglessness (Patterson & Staton, 2009; Yalom, 1980, 2002). Persons with progressive and/or acquired non-visible illness/disabilities may also be faced with "perceived uncertainty in illness" which means the inability to structure personal meaning or a cognitive schema of illness-associated events due to the unpredictability of their impairments (Livneh & Antonek, 2005, p. 13). Still, Söderberg, Lundman, and Norberg (1999), in their study on the meaning of women's experience living with fibromyalgia, show that persons with illness are seeking explanations beyond their body's impairment, "in order to give their illness a meaning and a coherence" (p. 584).

In face of existential issues such as meaninglessness, several studies have pointed to the finding that meaning making and purpose in life may assist persons with progressive and/or acquired non-visible illness/disabilities to mediate negative emotional states and have psychological and health related benefits. Maintaining engagement in valued activities and meaning making may be central to the quality of life of those with progressive and complex conditions (Mueller et al., 2020; Warnecke, 2017). Canda (2001) in his study on transcending through disability and death: transpersonal themes in living with CF, sought to understand ways that adults with CF use transpersonal beliefs and experiences to achieve a sense of transcendence by working through experiences of disability and death. Findings showed that due to health challenges and awareness of mortality many described themselves as being keenly interested in the meaning and purpose of life, high quality social relationships, appreciation for life, and attention to one's spiritual life (Canda, 2001). As participants' physical condition declined a sense of overall personal well-being and spiritual vitality concomitantly increased helping them to cope (Canda, 2001, p. 121). Graham, Lobel, Glass, and Lokshina (2008), in their study on the effects of written anger expression in chronic pain patients and making meaning from pain, found that meaning making "did significantly predict less depressed mood at nine weeks, even after controlling for expressed anger" (p. 208). Smith and Zautra (2004), in their research on purpose in life (PIL) in recovery from knee replacement surgery for those with osteoarthritis, had similar results: "when considered alone, PIL was related to less anxiety, depression, negative affect, functional disability, stiffness, and more positive affect" (p. 197). The findings of the study supported interventions, such as Viktor Frankl's logotherapy, that increase purpose and meaning in living and may help persons with health challenges to lead a more fulfilling life (Smith & Zautra,

2004). Finally, Dezutter, Luyckx, and Wachholtz (2015), in their study on meaning in life in chronic pain patients over time established that:

> The ability to find meaning and purpose despite physical challenges can change the lens through which the individual views the destabilization events in his/her life. Experiencing a strong sense of meaning can enhance the adjustment to a major stressor such as chronic pain by replacing a 'threat' perspective by a challenge perspective (p. 394).

Like the previous study, the authors conclude that their empirical findings substantiate existential theorists such as Frankl's who put forth the importance of meaning in life for coping with severe life stressors (Dezutter et al., 2015).

In that several studies support the import of meaning making and purpose in life in improving the lives of those with progressive and/or acquired non-visible illness/disabilities, and some explicitly mention Viktor Frankl's existential theory and logotherapy, I shall elaborate on his ideas here. Frankl (1963, 1963/2006, 1967, 1975, 1986, 1997, 2014) and Alex Pattakos (2010), who has translated Frankl's principles into the world of work, refer to the feeling at a spiritual level that one's life has no purpose or meaning as existential frustration which may be experienced as "an existential vacuum" (Frankl, 1967, p. 140). Frankl developed logotherapy, as an adjunct to any system of psychotherapy, when existential frustration and meaninglessness become forefront in clients' lives (Frankl, 1963/2006; Langle, 2006; Yaniger, 2011). Frankl posited seven core principles that form the foundation of logotherapy and act as guidelines to help clients to find purpose and meaning in life - freedom of will, will to meaning, meaning in life, hyper-intention and paradoxical intention, humour and self-detachment, hyper reflection and de-reflection and self-transcendence. The first of the three core principles relate to Frankl's philosophy whilst the latter best summarize the underlying psychological tenets of his theory. It is important to note that

Frankl honed his philosophy, psychology, and method of psychotherapy - logotherapy- whilst a prisoner in Nazi concentration camps during the second world war (Langle, 2006). That man can choose his attitude despite circumstance, the idea that man's basic motivation is the striving for meaning, the formulation of therapeutic techniques based upon coping mechanisms witnessed in the camps, and finally, the concept of self-transcendence, all generate from Frankl's experience (Bettlheim, 1980; Boynton et al., 2011; Farra, 2012; Langle, 2006; Pattakos, 2010; Yaniger, 2011). Frankl's seven core principles, also posited by Alex Pattakos, are elaborated upon here with embedded examples of how they can help those with progressive and/or acquired non-visible illness/disabilities who are struggling with meaninglessness (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Frankl et al., 2010; Pattakos, 2010):

3.3.1 Freedom of Will

We have freedom of will, the freedom to choose our attitude given any circumstance, even in the face of suffering. We are not just victims of circumstance but have the responsibility and freedom to choose our outlook on life. We have predetermined and disadvantageous conditions but are not prisoner to our instincts. In the instance of those with progressive and/or acquired non-visible illness/disabilities, many may struggle with their impairments. They require time to integrate their experience, process their feelings, grieve, and negotiate their relationships given their health situation (Graham et al., 2008; Gordon et al.,1998; Gray & Fossey, 2003; Hoppe, 2013; Lingsom, 2008; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Sturge-Jacobs, 2002; Valeras, 2009, 2010). At some point there are moments of choice. Some may isolate themselves and feel stuck in anger whilst others reach out to loved ones and try to maintain their sense of hope. This is not static but an evolving situation, involving multiple decisions (Büssing et el., 2010; Davis, 2005; Fitzgerald & Patterson, 1995; Hoppe, 2013; Juuso et al., 2011; Lingsom, 2008;

Livneh & Antonak, 2005; Nutting & Amos, 2020; Valeras, 2009, 2010; Varilek & Isaacson, 2020). Differences in attitude may be impacted by the veracity of support systems, social determinants of health and the severity of one's health situation, amongst many factors (Büssing et al., 2010; Gray & Fossey, 2003; Hoppe, 2013). There are studies that show that finding the positive in experiences such as illness/disability are not just possible but adaptive (Büssing et al., 2010; Hareide et al., 2011; Hoppe, 2013; Juuso et al., 2011; Psarra & Kleftaras, 2013; Sunderland et al., 2009; Varilek & Isaacson, 2020). Hoppe (2013), in her study on chronic illness as a source of happiness found that, although impairment is challenging, "happiness and disability are not mutually exclusive" (p. 275). Persons with chronic illness can experience happiness both despite their illness and because of it (Hoppe, 2013). Counsellors and psychotherapists can assist persons with progressive and/or acquired non-visible illness/disabilities, by not only helping them to process their grief but also assisting them to foster a realistic sense of meaning and hope, even happiness (Büssing et al., 2010; Hoppe, 2013; Nutting & Amos, 2020; Varilek & Isaacson, 2020). The following is a quote from Canda's (2001) study on transcending through disability and death, showing an adult with CF choosing to find positive attributes in the face of illness:

> Choosing to deal with cystic fibrosis, one can find positive attributes that outweigh the hardships involved. From this, we seem to develop an acute awareness and sensitivity to our lives and to life around us. With the realization that our lives may be shorter, we can seek opportunities to enhance the quality of our lives (quoted in Lab & Lab, 1990, p. 146). (Canda, 2001, p. 113).

3.3.2 Will to Meaning

We have a will to meaning. We are not only free, but most importantly we are free *to* something– free to achieve purposes and goals and to search for meaning. Human beings live in

three dimensions: the somatic, the mental and the spiritual. It is from our uniquely spiritual dimension that we strive for meaning. If we have meaning in our lives, then we can bare anything, even our own suffering or that of others. Meaning or purpose can be discovered in three different ways: by creating work or accomplishing a task, by experiencing something fully such as loving somebody and by the attitude that one chooses toward unavoidable suffering. Our will to meaning allows us to find purpose even if we find ourselves having to begin anew. In the instance of those with progressive and/or acquired non-visible illness/disabilities, impairment may lead to new perspectives, and a transformation of values, valued activities, purpose, and goals (Bishop, 2005; Dezutter et al., 2015; Hoppe, 2013; Lingsom, 2008; Lorenz, 2010; Mueller et al., 2020; Patterson & Staton, 2009; Shakespeare & Watson, 2001). This value change has to do with perceived losses and focusing on "satisfactions that are accessible" (Bishop, 2005, p. 9). Counsellors and psychotherapists may assist clients in the process of adaptation by helping them to re-evaluate their participation in present and previous life domains and engage in new interests and social outlets to gain more satisfaction (Bishop, 2005, p. 11). Persons who had been invested in their career, for example, may now attribute more purpose and meaning to other life domains such as their relationships (Bishop, 2005). As example of the will to meaning, a participant with chronic illness in Hoppe's study has found new goals and meaning in family:

> I had to search for a new goal, a new set of goals. And I suppose those goals, they have been in various forms, obviously I know my kids better, I know my wife better, and we are all, I think, happier and more comfortable. My wife had to change her work style too (Hoppe, 2013, p. 272).

3.3.3 Meaning in Life

We can find meaning in all of life's moments and it is our responsibility to be alert to what is uniquely meaningful to us (Wong, 2010). Meanings are not static but change from moment to moment and are contextual. Meaning rests in appreciation of the moment, in gratitude, in awareness, and in relationship. When our awareness is focused only on the future, we lose all connection to now — where we are, where others are, and where the meaning is. When we aren't grateful for the meaning in our life right now, we aren't honouring ourselves or others (Pattakos, 2010 Chapter seven, para. 36). In terms of those with progressive and/or acquired non-visible illness/disabilities, some may make a commitment to live life in the moment, at a new pace and with more authenticity given their impairment (Patterson & Staton, 2009). Counsellors and psychotherapists may assist clients by helping them to slow down and pay attention to their meaning "fuel gauge" to determine if their life is in alignment with their important values (Pattakos, 2010). As example of finding meaning in the moment in alignment with one's newfound values, a participant with chronic illness in Hoppe's study describes how he has been reborn and is enjoying newfound pleasures:

> Now I do the soccer coaching here, I bring the lads down, watch them play. I don't think I'd be able to kick a ball now, my balance wouldn't let me. My life changed completely, yeah it did. I had to readdress; I suppose I had to be reborn. I had to be reborn, I had to change my life completely. Where I would have been an outgoing night person, enjoy life, enjoying life to the full, party wise and all that same song, everything […] I can't do that anymore now. But I don't mind. I am quite enjoying being at home now and sit down with a nice glass of wine. It's all now completely different going from one extreme to the other (Hoppe, 2013, p. 271).

3.3.4 Hyper-intention/Paradoxical intention

We can discover how we thwart our intentions, thereby freeing ourselves to find meaning in the moment. It is important that we do not become fixated on a future goal (hyper-intention) or we may see only problems (hyper-reflection), miss the meaning of the moment and work against ourselves (paradoxical-intention). For example, we may become so consumed with getting a job promotion that we begin to see ourselves failing to achieve it, develop anticipatory anxiety, not do well in an interview thereby creating a self-fulfilling prophecy. In logotherapy the technique of paradoxical intention invites clients to identify and welcome their fears, thereby ultimately letting them go and taking their power to control them away. When no longer fearful, meaning can be found in appreciation of the moment. In the instance of those with progressive and/or acquired non-visible illness/disabilities, it has been illustrated that some clients will postpone acknowledging their functional capacity for fear that this will lead to abandonment from family members who might perceive them as more capable than they are (Patterson & Staton, 2009). If fear persists, it may sabotage the very things that they strive for - authentic relationships and independence (Patterson & Staton, 2009). Counsellors and psychotherapists can assist clients by being empathically present for their fear allowing it to dissipate, helping them to process feelings of loss and grief, and find true meaning and purpose (Folzer, 2001; Patterson & Staton, 2009).

3.3.5 Humour and Self-detachment

We can employ humour and self-detachment to cope with any difficulty. We can laugh at ourselves and our situation, as well as look at ourselves from a distance to gain insight and perspective. By distancing ourselves from our misery we can externalize it and take misery's power away. Humour and self-detachment are effective coping tools for getting through stressful situations, but their real value lies in helping us to gain perspective, rise above our problems and find meaning in the moment. In the instance of those with progressive and/or acquired non-visible

illness/disabilities, counsellors and psychotherapists may employ treatments such as narrative therapy and others which separate and externalize the problem from the person. This helps clients to gain perspective, find new strengths and abilities, and reconnect with what's meaningful to them (Block & West, 2013; Nochi, 1998).

3.3.6 Hyper-reflection and De-reflection

We can shift our focus of attention when we are coping with difficult situations and thus find meaning. When we are faced with a problem situation instead of over focusing on it (hyper-reflection) we can de-reflect and focus instead on values that are important to us. In logotherapy the technique of de-reflection invites clients to redirect their attention from their obsessive thoughts about a problem to other values and sources of meaning in their lives (Boynton et al., 2011). In the instance of those with progressive and/or acquired non-visible illness/disabilities, some clients may experience anxiety when they overfocus on no longer being able to perform as they once did, lose their sense of self efficacy and find their sense of self altered (Bishop, 2005; Patterson & Staton, 2009). Counsellors and psychotherapists can help by listening carefully to their story, placing problems in perspective, reframing negative self-attributions, and having them begin to think about their values, and attainable and meaningful goals (Boynton et al., 2011; Patterson & Staton, 2009).

3.3.7 Self-transcendence

We can rise above our suffering by serving others thereby making our own lives and that of others richer. Whenever we go beyond our own personal needs and serve others, we enter the realm of self-transcendence. Viktor Frankl, Nelson Mandela, Mahatma Gandhi and the Dalai Lama all transformed their suffering into service and in so doing experienced their suffering as meaningful. Toward the end of his life Maslow, who had been in frequent contact with Frankl,

agreed: in extending beyond ourselves to help others we find self-transcendence and therefore ultimate meaning. Others such as Wong (2010) also agree: "meaning in life is limited and unsustainable without reaching out for something greater and higher than self-interest" (p. 87). In the instance of those with progressive and/or acquired non-visible illness/disabilities, counsellors and psychotherapists may help clients by first validating their experience and, when ready, helping them to reach out beyond themselves to offer help to others thereby finding ultimate meaning (Psarra & Kleftaras, 2013). Though continuously aware of her finiteness, one participant in the study by Varilek & Isaacson (2020) on the dance of CF describes finding meaning and joy in helping others:

> How can what I have to deal with, how can that help other people? It's not, it's not all about me and my problems, but you know, I'm the type of person, and I find value [in] how much I can enrich somebody else's life or how much I can help somebody else. So, I don't have a choice. I mean, you're dealing with this and it can be so much worse, but you know, the more positive you stay, the more positive energy that you attract around you, [the better] I am (p. 3559).

In summary, those with non-visible illness/disabilities, may experience existential and spiritual issues in terms of aesthetic and existential anxiety as well as questions regarding meaning and purpose in life, particularly when they are confronted with a progressive and/or acquired non-visible illness/disability (Block & West, 2013; Carroll & Coetzer, 2011; Dezutter et al., 2015; Fitzgerald & Paterson, 1995; Graham et al., 2008; Lingson, 2008; Lorenz, 2010; Pachankis, 2007; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Sturge-Jacobs, 2002). In face of existential issues such as meaninglessness, several studies have pointed to the finding that meaning making and purpose in life may assist persons with progressive and/or acquired non-visible

illness/disabilities to mediate negative emotional states and have psychological and health related benefits. This is consistent with Viktor Frankl's seven principles and logotherapy (Carroll & Coetzer, 2011; Dezutter et al., 2015; Graham et al., 2008; Livneh & Antonal, 2005; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Schleicher et al., 2005; Smith & Zautra, 2004). According to Frankl's seven fundamental philosophical and psychological principles and logotherapy - freedom of will, will to meaning, meaning in life, hyper-intention and paradoxical-intention, humour and self-detachment, hyper-reflection and de-reflection and self-transcendence - in the instance of those with progressive and/or acquired non-visible illness/disabilities: meaning can be found by choosing one's attitude, finding new purpose and meaning, finding meaning in the moment, setting aside one's fears in an empathetic therapeutic relationship, separating the problem from the person, shifting one's focus from problems to attainable and meaningful goals, and serving others.

In this chapter, I have endeavored to describe the mental health, identity, existential & spiritual issues of persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities. In the following chapter I will discuss counselling and psychotherapy with persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities: suggested practices, guidelines, and a gap in the research literature.

Chapter 4: Counselling and Psychotherapy with Persons with Non-Visible Illness/Disabilities and Progressive and/or Acquired Non-Visible Illness/Disabilities: Suggested Practices, Guidelines, and a Gap in the Research Literature

Multiculturalism and the requirement to be culturally competent have become powerful forces among mental health professionals but one population which has received less attention within this body of literature are those with disabilities (Artman & Daniels, 2010; Barsky, 2018;

Olkin, 2007; Waters & Asbill, 2013). Cultural competence can be understood as a process not an end, with the client being the expert in their own experience and the counsellor embracing a stance of cultural humility acknowledging that we are continuously learning (Barsky, 2018; Waters & Asbill, 2013). Recent cultural competence and treatment adaptation studies have shown that culturally informed practice yields efficacious psychotherapeutic treatments in large part because this creates a feeling in clients that they are being fully understood (Chu et al., 2016; Olkin, 2007). Counsellors that work with persons with disabilities and their families must understand the experience of disability in all of its dimensions- individual, social, and political (APA, 2012; Artman & Daniels, 2010; Chu et al., 2016; Cornish et al., 2008; Johnson, 2011; Leigh et al., 2004; Livneh & Antonek, 2005; Olkin, 2007; Oliver, 1995; Smart & Smart, 2006; Packard, 2006; Simpson & Thomas, 2014; Strike et al., 2004; Stuntzner & Hartley, 2014; Warnecke, 2017). The ethical component in engaging in culturally competent practice in the area of disability has been highlighted by Warnecke (2017), in his study on chronic fatigue phenomena. In one example, he describes the experience of a client with Autism, who spent 18 months in complete silence with an analyst "who appeared unable to adapt the clinical approach to allow for difference, which left the client with no alternative but to end therapy eventually" (Warnecke, 2017, p. 278). He equates this with the experience of those with chronic fatigue syndrome whose therapists fail to schedule appointments for a peak time of day, thereby missing the opportunity to work constructively with the complexity of this impairment (Warnecke, 2017).

Cultural competence when applied to persons with disabilities in the context of counselling and psychotherapy, can improve quality of care, clinical engagement, and therapeutic outcomes such as the reduction in depressive symptoms (Artman & Daniels, 2010; Chu et al., 2016; Cornish et al., 2008; Olkin, 2007; Warnecke, 2017). Chu et al. (2016) have found that "cultural competence

works because it creates: a contextual match with clients' external realities; (b) an experiential match in the microsystem of the therapeutic relationship or framework; and (c) an interpersonal feeling of being understood and empowered within the client" (p. 18). Guidelines for counselling and psychotherapy may assist therapists in becoming more culturally competent by providing them with vital information regarding the many voices, problems, strengths, and abilities, of those with disabilities thereby enhancing the effectiveness of their interventions (APA, 2012; Stuntzner & Hartley, 2014). Guidelines may also help therapists to better conceptualize working with those with disabilities so that they may provide professionally and ethically sound services (APA, 2012; Stuntzner & Hartley, 2014). Persons with non-visible illness/disabilities and progressive and/or acquired von-visible illness/disabilities, are faced with unique challenges and many mostly qualitative and quantitative studies as well as conceptual articles in various disciplines have sought to give their experience voice. Some of these authors have also suggested practices and guidelines to meet the needs of this population. In 2012, the American Psychological Association (APA) developed guidelines for assessment and intervention with persons with disabilities (APA, 2012). The guidelines were developed by the APA's Task Force on Guidelines for Assessment and Treatment of Persons with Disabilities after an extensive literature search and feedback on findings (APA, 2012). The following are suggested practices and guidelines relevant to working with persons with non-visible illness/disabilities and progressive and/or acquired von-visible illness/disabilities, gleaned from the authors of mostly qualitative and quantitative studies, as well as the conceptual literature and from the APA (2012):

- Do not make assumptions based only on what you can see;
- Do not assume that clients have sought counselling solely because of their disability. Instead, be open to all presenting issues;

- Do convey belief in clients' perceived experiences. Understand that persons with non-visible illness/disabilities may have had traumatic experiences with previous therapists who have not believed them or attributed their illness to psychological factors, which has undermined their self-confidence and self - esteem. Understand that there may be a power differential between counsellor and client if the former is not disabled. Address this issue openly with clients if this becomes a barrier to treatment. Where relevant, speak with clients about joining a support group with like others which may be helpful to validate and legitimize their experience;
- Do pay attention to clients' possibilities, strengths and abilities and incorporate these into the counselling process. Understand that most clients do not live their lives focused on their disability. Treat persons with disabilities as whole persons, of which disability is part of their experience;
- Do understand that disability is not solely physiological but also because of clients' interaction with the environment. Clients' emotional responses may be about what they are up against, for example, insensitive behavior and barriers such as intransigent workplace schedules. Help them to discern which barriers are within their control to change and what strategies they can employ to help themselves;
- Do employ a humanistic stance -being fully present, caring, and empathetic - and practice cultural competence - appreciate the unique experience of each individual client and allow for flexibility in your approach. Attend disability awareness training and supervision. Take care to not conflate physiological symptoms with psychological symptoms such as depression;

- Do understand the impact that disability language has on your clients, particularly in terms of their sense of identity. Employ person first language, for example, person with ----- (name of illness/disability), especially when unsure. There are those in the disability community who prefer disability first language, such as "Deaf person." When uncertain regarding what language to use with your client or how they identify, ask about their personal preference;
- Do educate oneself on the different models of disability and how these have affected your attitudes and biases which may impact your counselling interventions. Understand which model(s) your clients are influenced by/ adhere to because this may impact important factors such as their sense of self-efficacy. Understand the definitions of disability under federal and provincial law as well as accommodation requirements and remedies in the instance of discrimination;
- Do pay attention to existential issues such as the meaning that clients' attribute to their illness/disability as well as whether they have a sense of purpose in life. Helping clients to develop interest in life domains that are accessible and align with their values may help them to cope;
- Do familiarize oneself with disability resources in one's community and provide resource information and educational material, where appropriate and requested. Ensure that clients' voices are paramount in all referral decisions;
- Do be inclusive of family members/significant others as they interact with clients daily, may be experiencing stress and are a main source of support;
- Do provide a barrier free environment and individualized accommodations re: lighting, seating, noise levels as clients might display sensitivities. Allow for scheduling alterations-

spacing sessions out, optimal time of day, pausing, video and telephone counselling sessions in the event that your client is experiencing an exacerbation (APA, 2012; Bassler, 2009; Bogart, 2014; Bishop, 2005; Büssing et al., 2010; Carroll & Coetzer, 2011; Chamberlain, 2006; Chu et al., 2016; Cornish et al., 2008; Davis, 2005; Dezutter et al., 2015; Dickson et al, 2007; Evans, 2017; Figueiredo & Griffith, 2016; Folzer, 2001; Gordon et al.,1998; Graham et al., 2008; Gray & Fossey, 2003; Hareide et al., 2011; Hoppe, 2013; Judd & Wilson, 2005; Juuso et al., 2011; Karagiorgou et al., 2017; Lingsom, 2008; Lorenz, 2010; Mueller et al., 2020; Mukherjee et al., 2003; Nochi, 1998; Olkin, 2007; Packard, 2006; Patterson & Staton, 2009; Pinxsterhuis et al., 2015; Prigatano, 1991; Psarra & Kleftaras, 2013; Schleicher et al., 2005; Smart & Smart, 2006; Söderberg et al., 1999; Stone, 2005; Stuntzner & Hartley, 2014; Sturge-Jacobs, 2002; Sunderland et al., 2009; Taylor, 2005; Titchkosky, 2001; Ward et al., 2008; Warnecke, 2017; Valeras, 2009, 2010; Weatherhead & Newby, 2011).

The above suggested practices and guidelines, all applicable to those with non-visible illness/disabilities and progressive and/or acquired von-visible illness/disabilities, have been proposed by many authors in various disciplines in an effort to provide a framework for culturally informed and efficacious practice. Whilst they appear comprehensive, most are informed by conceptual articles or by studies employing qualitative or quantitative methodology, with the researcher in charge of the design, implementation, and dissemination of results (Valeras, 2010). Whereas the APA Task Force has employed a comprehensive literature review, it is unclear to what extent they have consulted with persons with non-visible illness/disabilities, who have engaged in counselling and psychotherapy themselves, in the development of guidelines. As the APA guidelines are geared to all those with disabilities, they may obfuscate the experience of those

with non-visible illness/disabilities and progressive and/or acquired von-visible illness/disabilities, who contend with unique psychosocial factors (Olkin, 2007).

There is a call for PAR in counselling and psychotherapy studies and with those with disabilities developed by and for them, in alignment with the disability slogan, "nothing about us without us" (Ashby, 2011; Balcazar et al., 2004, 2006; Borg et al., 2012; Kidd & Kral, 2005; Lezzoni & Long-Bellil, 2012; Minihan, 2004; Olkin, 2007, p.10; Parkinson, 2006; Spong & Waters, 2015). The disability community has expressed a need for inclusive, action-based research methodologies in which people with disabilities function as partners and consultants, not as research subjects (Bergold & Thomas, 2012; Borg et al., 2012; Kitchin, 2000; Newman et al., 2014; Stone & Priestley, 1996). PAR has emerged as a viable alternative to conventional research (Smith, Rozenzweig et al., 2010). Involving persons with disabilities in research about their lived experience yields results which are culturally relevant, often with unique, unexpected, and creative outcomes, that one would not achieve through qualitative or quantitative research (Balcazar et al., 2004, 2006; Lorenz, 2010). The direct involvement of persons with disabilities in the research process facilitates a more accurate, contextualized, and authentic analysis of their personal and social reality (Balcazar et al., 2006). PAR studies benefit from the experience-based knowledge of those with disabilities in that results are more relevant to their struggles, meaningful and impactful (Ashby, 2011; Minihan et al., 2004; Pakhale, Kaur et al., 2016; Pakhale et al., 2018; Stone, 2005; Stone & Priestly, 1996; Smith, Rozenzweig, et al., 2010). PAR is empowering as end users of intervention services become aware of their personal resources and ability to potentiate change in their lives (Balcazar et al., 2004, 2006; L'Etang & Theron, 2011; Pakhale, Kaur et al., 2016; Pakhale et al., 2018; Smith, Rozenzweig, et al., 2010).

Knowledge constructed without the equal participation of those effected by a problem can only be partial knowledge (Kidd & Kral, 2005; Kidd et al., 2017; Pakhale, Kaur et al., 2016; Pakhale et al., 2018). As such PAR endeavors to incorporate the experience-based knowledge of end users of services by including them as co-researchers involved in every aspect of the research from decisions regarding Topic Guide questions to dissemination of results (Cook, 2012; Kidd & Kral, 2005; Pakhale, Kaur et al., 2016; Pakhale et al., 2018; Smith, Rozenzweig, et al., 2010). Their equal involvement in research about them is important for those with disabilities, many of whom find others circumscribing their lives, resulting in services that are not in alignment with their needs (Ashby, 2011; Bayliss et al., 2008; Charlton, 2000; Davis, 2005; Deegan, 2005; Hultberg, 2012; Jones, 2007; NARIC; Minihan et al., 2004, 2011; Olkin, 2007; Riecken et al., 2005; Shakespeare, 1996; Stone, 1995; Street et al., 2009). Within families, health care systems and research persons with disabilities feel that they are often talked at, researched about, and decided for (Bassler, 2009, 2014; Hultberg, 2012; Reicken et al., 2005; Stone & Priestley, 1996). This is particularly true for persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities who have difficulty being believed because their limitations are not immediately obvious and "therefore are assumed to be less real or less difficult than the struggles of people with more apparent disabilities" (Bassler, 2009, 2014; Reicken et al., 2005; Sharma et al., 2020; Valeras, 2009, 2010, p.7). A recurring conversation centres around finding a way to be heard within families and institutions that often misunderstand the nuance of their experience (Davis, 2005; Hultberg, 2012; Shakespeare, 1996; Sharma et al., 2020; Stone, 1995).

A key development in participatory research with persons with disabilities has been in health care provision. Participatory health research (PHR) has included persons with disabilities

as co-researchers, with the latter generating solutions, and positively impacting both program evaluation and service delivery (Armstrong, 2009; Balcazar et al., 2004; Deegan, 2005; Etowa et al., 2007; Marshall et al., 2008; Minihan et al., 2004; Riecken et al. 2005). PHR has developed in response to the growing body of literature which has documented problems with the care that people with disabilities receive from their health care providers. Persons with disabilities feel that health care providers are not adequately trained to treat them and do not possess the skills to effectively communicate and develop trusting relationships with them (Conill, 1998; Duggan et al., 2009, 2010; Invisible Disabilities Association; Minihan et al., 2004; Wells, 2002). Minihan et al. (2004), aimed to improve the quality of care provided persons with disabilities. They created a disability curriculum at Tufts University to improve the knowledge and skills of medical students working with those with disabilities, utilizing participatory research. Persons with physical or sensory disabilities were involved in every aspect of the research from design to implementation and played a pivotal role in outlining the preferred attitudes and skills of medical students in interviewing them. They were involved in simulated medical interviews with medical students as Standardized Patient Educators and gave constructive feedback to students regarding the integration and use of preferred attitudes, knowledge, and skills. They were the primary evaluators of students' performances. Persons with disabilities decided on the following guidelines for medical students: treat patients with respect; be collaborative; understand that persons with disabilities have functional lives; and be aware that inaccessible medical settings create barriers to good patient care (Minihan et al., 2004). The study was successful in that the feedback from participants -both students and Standardized Patient Educators - was positive and medical students now participate in this curriculum each academic year. The teaching exercise conveys to students

the importance of humility and learning from persons with disabilities, who have more intimate knowledge about their condition than medical students and physicians (Minihan et al., 2004, 2011).

Whilst there is progress in PHR, there is a gap in the research literature for participatory action studies (PAR) in the field of counselling and psychotherapy and specifically with persons with disabilities (Kidd and Kral, 2005; Kidd et al., 2017; Olkin, 2007; Simpson & Thomas, 2014; Spong & Waters, 2015). This may be in part due to the lack of engagement between clinical psychology and disability studies (Foley-Nicpon & Lee, 2012; Olkin, 2007; Ponterotto, 2010; Simpson & Thomas, 2014). Disability is often misunderstood by counselling professionals and psychotherapists as well as society (APA, 2012; Cornish et al., 2008; Johnson, 2011; Oliver, 1995; Olkin, 2007; Stuntzner & Hartley, 2014). Counselling professionals are "subject to the effect of societal and historical beliefs pertaining to disability and may inadvertently contribute to the perceptions of people with disabilities as diseased, broken, and in need of fixing without an understanding of this perspective" (Stuntzner & Hartley, 2014, pp. 1-2). These negative beliefs do not necessarily match up with the reality of those with disabilities who may have a variety of experiences including happiness and a sense of meaning and purpose in life (Canda, 2001; Carroll & Coetzer, 2011; Dezutter et al., 2015; Graham et al., 2008; Hareide et al, 2011; Hoppe, 2013; Johnson, 2011; Livneh & Antonal, 2005; Lorenz, 2010; Oliver, 1995; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Schleicher et al., 2005; Shakespeare, 1996; Smith & Zautra, 2004; Varilek & Issacson, 2020). Lack of information may result in focusing on the impairment of those with disabilities without paying sufficient attention to the disabling effects of social barriers (Bassler, 2014; Davis, 2005; Lingsom, 2008; Oliver, 1995; Olkin, 2007; Shakespeare, 1996; Stone, 1995; Valeras, 2010). Persons with disabilities may be perceived as a homogenous group, which belies the reality of their experience (Oliver, 1995; Olkin, 2007). Counsellors may be misinformed

about clients' medical conditions which may lead to them feeling devalued, for example, when one attributes physiological symptoms to depression or malingering (Olkin, 2007; Ward, Hogan, Stuart, & Singleton, 2008). Underlying misunderstandings is the fact that clinical counselling and psychotherapy programs do not provide an adequate amount of training, knowledge, or supervision regarding the experience of disability and this may negatively impact therapeutic outcomes (Olkin, 2007; Oliver, 1995; Parkinson, 2006; Stuntzner & Hartley, 2014, Ward et al., 2008). Clinical guidelines are required particularly for populations with complex co-morbidities and those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities to improve practices and health care outcomes (Bayliss et al., 2008). Including those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities in PAR in counselling and psychotherapy fills a gap in the research literature. It will ensure that findings are relevant, meaningful and the process empowering. It will inform counsellor knowledge and help us to provide culturally competent and cogent practices (Artman & Daniels, 2010; Ashby, 2011; Balcazar et al., 2004, 2006; Bergold & Thomas, 2012; Borg et al., 2012; Chu et al., 2016; Cook, 2012; Cornish et al., 2008; Creswell et al., 2007; Faulkner, 2008; Kidd & Kral, 2005; L'Etang & Theron, 2011; Lezzoni & Long-Bellil, 2012; Lorenz, 2010; Macdonald, 2012; Olkin, 2007; Parkinson, 2006; Riecken et al., 2005; Smith, Rozenzweig, et al., 2010; Spong & Waters, 2015; Warnecke, 2017). I shall now briefly outline three important examples of PAR with those with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities that are foundational to my research.

Chapter 5: Three Foundational Examples of PAR with Persons with Non-visible Illness/Disabilities and Progressive and/or Acquired Non-Visible Illness/Disabilities

The following three studies exemplify the essence of PAR, in that they include participants with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities as co-researchers and yield rich suggestions for service providers. Although none are in the field of counselling and psychotherapy the results are very relevant to practice in this field. Deegan (2005) aimed to understand how people with psychiatric disorders demonstrated resilience in the way that they used or did not use psychopharmacological medications. Twenty-nine persons diagnosed with psychiatric disorders were interviewed and integrated into a partial participatory project. Findings showed that patients were dissatisfied with their psychiatrist's dependence on psychopharmacology to treat them and agreed that their medication adherence would significantly improve if the latter would inquire substantively about their personal medicine. Personal medicine was found to include two categories: activities that give meaning and purpose to life and self-care strategies. According to patients, personal medicine helped to decrease symptoms, avoid hospitalizations, and improve an overall sense of well-being (Deegan, 2005). Significantly, only four of the 29 participants reported that their psychiatrists inquired about personal medicine, and many did not share their self-care strategies with them for fear of disapproval (Deegan, 2005). Deegan (2005) concluded that psychiatrists would serve their patients better if they would work collaboratively with them to inquire about personal medicine and include it as part of their overall treatment plan. Power statements were developed in collaboration with participants to present to psychiatrists and mental health providers that would impress upon them the importance of personal medicine in their overall recovery (Deegan, 2005). Riecken et al. (2005) aimed to demonstrate the ethics of voice in the writing of academic research, based on the project Traditional Pathways to

Health, a preventative suicide program for Aboriginal youth (authors' wording). Findings showed that Aboriginal youth were dissatisfied with care providers concentrating on their unhealthy practices and would prefer that they focus instead on Aboriginal sources of wellness and self-determination to facilitate healing (Riecken et al., 2005). The project included Aboriginal youth as co-researchers and had them chose their own mode of communication - video projects and speaking about the projects in circles of presentation – as a vehicle to share their preferences with care providers (Riecken et al., 2005). Lorenz (2010), aimed to gain a better understanding of the lived experience of persons with brain injury by employing photovoice. Photovoice is a PAR approach which helps participants to represent and share their lives with others through photographs and text (Lorenz, 2010). Brain injury survivors identified nine themes through their photographs which captured their experience of brain injury - "the journey; lost dreams; chaos; challenges; strategies; my advocacy story; comfort and support; acceptance; and hope for the future" - and later prepared an exhibit with a view to informing and educating peers, policy makers and service providers (Lorenz, 2010, p. 220). The studies of Deegan (2005), Reiken et al. (2005) and Lorenz (2010) highlight the importance of including persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities as co-researchers, tapping into their experience-based knowledge as opposed to solely the voices of researchers, which yielded creative and unique outcomes. PAR yielded end users' views for service providers on how we can better understand their lived experience and intervene in a way that is relevant and efficacious to them (Lorenz, 2010). These PAR studies are in alignment with the literature on cultural competence and humility, highlighting the importance of mental health providers and others learning from those that we serve. In addition, PAR empowered those with

mental health issues and brain injury to speak their truth, the methodology itself a vehicle for healing.

This research study builds upon the example of Deegan (2005), Riecken et al. (2005) and Lorenz (2010), including those with CF as co-researchers privileging their voices in the development of A Patient-Centred Framework for Counselling and Psychotherapy in alignment with their needs to better serve them, to get it right. It has also been inspired by the work of Minihan et al. (2004), whose work in participatory health research with those with disabilities informed the practice of medical students and continues to do so today. In the following chapter I shall delve into CF and further the case for A Patient-Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis.

Chapter 6: Cystic Fibrosis and the Case for A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis

CF is the most common genetic illness/disability in Canada and the United States (Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Maras et al., 2018). Approximately, one in every 3600 children born in Canada has CF (Cystic Fibrosis Canada, n.d). In the United States, CF affects approximately one in every 2500 – 3500 newborns (Centers for Disease Control and Prevention, 2022; Cystic Fibrosis Foundation, n.d; Gan et al., 1995). There are 70,000 cases of CF worldwide (Cystic Fibrosis Foundation, n.d; Mueller et al., 2020). Sixty percent of those with CF are diagnosed during infancy, with others diagnosed later: in childhood, adolescence, or adulthood (Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Gan et al., 1995; Mueller et al., 2020; Nutting & Amos, 2020). CF occurs when a child inherits two copies of a recessive gene (one from each parent) - the cystic fibrosis transmembrane conductance regulator (CFTR) (Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Mueller et al., 2020; Quittner et al., 2016).

Mutations in the CFTR gene cause the CFTR protein, located in the exocrine system and responsible for regulating the flow of salt and water on many surfaces in the body, to not work properly. When the protein is not working correctly, chloride – a component of salt – becomes trapped in cells, water cannot hydrate the cell surface and thick mucus builds up (instead of being swept away) allowing germs to multiply and cause infections (Cystic Fibrosis Foundation, n.d; Mueller et al., 2020; Quittner et al., 2016). There are many CF mutations, causing one individual with CF to refer to those impacted as a "kingdom" of CF rather than a uniform population (Kramer-Golinkoff, 2014, p. 808). Nearly 50% of those with CF share two copies of the most common CF mutation, Delta F508, with 90% sharing at least one copy (Kramer-Golinkoff, 2014). This is significant because to qualify for a recent revolutionary medication which helps the defective CFTR protein work more effectively, Trikafta (approved by Health Canada in 2021), one must have at least one Delta F508 mutation and other requirements (Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Kramer-Golinkoff, 2014). CF is a multi-system disease (Maras et al., 2018; Quittner et al., 2016). It severely compromises the respiratory system (lungs, sinuses), digestive system, reproductive system, and other organs, most commonly the pancreas (Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Mueller et al., 2020). Chronic pain is a common symptom in CF with 89% of adults living with the illness experiencing it, particularly in the chest and abdomen (Maras et al., 2018; Pakhale et al., 2015). Persons with CF experience lung damage due to a chronic lung condition, bronchiectasis, which causes scarring of the airways and makes it difficult for the body to move air in and out of the lungs and clear mucus from the bronchial tubes. They may experience severe difficulty breathing related to lung damage, hemoptysis (coughing up blood) and face the difficult decision to undertake lung transplantation (Mueller et al., 2020). Lung disease is largely responsible for mortality (Maras et al., 2018;

Quittner et al., 2016). Most individuals with CF suffer from pancreatic deficiency and pancreatic enzymes must be taken with all food to maximize weight gain and minimize painful gastrointestinal symptoms. Individuals with CF typically must consume two to three times the calories than most individuals as they have trouble digesting their food and gaining weight (Mueller et al., 2020). Ninety-seven to ninety-eight percent of men with CF are sterile due to a blocked or missing vas deferens and possible fluid accumulation around the testes which interferes with how well they work. Women may have more trouble conceiving, because the mucus that coats the vagina and cervix is thicker making it difficult for sperm to travel up the reproductive track to fertilize an egg (Mueller et al., 2020). Although sexual desire is normal, there can be issues with the physical act of sex (Pakhale et al., 2015). Twenty percent of persons with CF will develop CFRD, due to thick sticky mucus scarring the pancreas thereby preventing it from producing normal amounts of insulin (Cystic Fibrosis Foundation, n.d; Mueller et al., 2020). CF is a progressive illness requiring many complex treatment hours and exercise to slow its advance and maintain optimal health (Besier & Golbeck, 2012; Mueller et al., 2020; Quittner et al., 2016). Despite recent treatment innovations, daily management is extremely time consuming and involves some variation of five primary approaches – airway clearance, nebulized medications, antibiotics, enzyme replacement pills and high calorie intake (Nutting & Amos, 2020). The life expectancy of those with CF has improved considerably in the last few years with the advent of CFTR modulators such as Trikafta – the life expectancy has increased from 27.5 years in 1986 to 51.8 years today in Canada - however, many still suffer from repeated exacerbations, hospitalizations and may pass away at a young age (Duff, 2015; Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Maras et al., 2018; Mueller et al., 2020; Pakhale, Baron et al., 2016). Many describe CF as a spectrum illness, with some individuals experiencing less severe symptoms

at least initially and others being so harshly impacted that it can be classified as a disability (Mueller et al., 2020). CF as a spectrum also applies to the fluctuating nature of the illness, where pulmonary exacerbations and other health complications can alternate with periods of relative health, most times unpredictably. The experience of CF is multi-layered and unique for each individual (Cystic Fibrosis Foundation, n.d; Mueller et al., 2020). CF is largely a non-visible illness/disability, however, coughing excessively, surgical, and other scars, for example, where a feeding tube or port has been inserted and removed, and the possible use of oxygen later in the illness may mean that it can become visible (Macdonald et al., 2019; Mueller et al., 2020; Oliver et al., 2014). CF's progressive nature and the possibility that one will develop CFRD and other complications plus the reality that some may be diagnosed later in life means that there are acquired aspects to the illness (Hjelm et al, 2020; Mueller et al., 2020). Having to cope with all these health factors increase the risk of mental health issues for those with CF.

Research on CF, and psychological well-being shows that most adjust well (Cronly et al., 2018; Godbeck et al., 2015). Nonetheless, persons with CF have rates of depression and anxiety two to three times greater than the rest of the population, sometimes aligned with disease progression (Besier & Golbeck, 2012; Garcia et al., 2018; Maras et al., 2018; Mueller et al., 2020; Pakhale et al., 2015; Quittner et al., 2014; Smith et al., 2016). In one study of CF patients in an inpatient health setting, the results showed not only an increased level of anxiety and depression but also suicidal ideation (Garcia et al., 2018). Nearly one half of those diagnosed with depression will also be diagnosed with anxiety (Smith et al., 2016). In the International Depression Epidemiology Study (TIDES), Quittner et al. (2014) conducted a large-scale psychological screening study across nine countries (Europe and the United States) to examine rates of anxiety and depression in adolescents and adults with CF, as well as parent caregivers. Regardless of

screening tool employed, results showed elevated depression in 17% of patients across countries, a rate two times that reported in community populations (9.2%). Similarly, rates of anxiety were elevated in patients with 30% above the clinical cut-off. Again, these rates are two to three times higher than typically reported (Quittner et al., 2014). Along with the mental health issues experienced by others with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities mentioned previously in this thesis - living in a "permanent state of conflict" (Davis, 2005, p. 189), the dilemma of concealment vs disclosure, the toll of disbelief– emotional difficulties can be associated with specific characteristics of living with CF, which I will outline here.

> As a teenager, I was, I was wild. My friends were like, "You know, you're going to die. Let's just do it good." So I tried to do it good. Like, I was drinking. I wouldn't do treatments. I was smoking weed. I was just like, "I'm going to die anyway. Who knows, might as well do it well." And after I ended up in the hospital, my mom was like, "Are we done? Let's get back on track." And I was able to get back on track and get where I'm at now, but it was tough... I just kind of gave up and wanted to do my own thing, I was around 15... I did everything to sabotage myself (Varilek & Isaacson, 2020, p. 3557).

Beginning in childhood, those with CF may notice that they are different than their peers and many had been told that their life expectancy would be significantly shortened. They therefore may not have planned for a full adult life, which is now for some a reasonable expectation (Macdonald et al., 2019; Mueller et al., 2020; Nutting & Amos, 2020; Quittner et al., 2016; Varilek & Isaacson, 2020). Whilst findings in one study show that most individuals with CF have aspired to or participate in paid employment others may have lashed out in adolescence against their fate, and now feel unprepared for a full adult life, and pressure to perform like everyone else despite

their limitations (Hogg et al., 2006; Macdonald et al., 2019; Nutting & Amos, 2020; Varilek & Isaacson, 2020). Related to this is the reality that not every person with CF will have access to disease modifying drugs due to lack of genetic suitability as well as financial and social factors, which can lead to alternating feelings of hope and hopelessness (Mueller et al., 2020). CF requires a daily treatment regimen which can be time consuming – often from two to four hours a day - and interfere with one's work and coveted time with friends and family (Maras et al., 2018; Mueller et al., 2020; Nutting & Amos, 2020: Quittner et al., 2016). Treatment adherence is considered generally poor with many seeing their daily regimen as burdensome (Maras et al., 2018; Mueller et al., 2020; Nutting & Amos, 2020; Quittner et al., 2016; Varilek & Isaacson, 2020). In addition, making time for treatments, medications, and high calorie meals means that one must begin one's day early and end late, which can interfere with sleep and negatively impact physical and mental health (Mueller et al., 2020). CF remains one of the most arduous chronic conditions to manage, with affected individuals and families having to balance its demands with the needs of the family unit (Nutting & Amos, 2020; Quittner et al., 2016). Family systems may handle the illness with resilience, lack of confidence and/or rigidity, with adaptation an evolving process (Nutting & Amos, 2020). Nutritional benchmarks are required to achieve optimal health, and this can lead to struggles with one's family when young, maladaptive eating and body image difficulties (Mueller et al., 2020; Nutting & Amos, 2020). CF can lead to a sense of isolation and loneliness as the fluctuating nature of the illness, exacerbations, and hospitalizations, means that individuals must miss out at times on peer activities, school, and work, making it difficult to form lasting friendships and affiliations (Varilek & Isaacson, 2020). CF is rare in that individuals carry bacteria within their lungs that could be harmful to others with the illness. Due to the risk of cross infection, individuals with CF cannot meet one another, robbing them of important peer support and increasing their

sense of social isolation (Goldbeck et al., 2014, 2015; Mueller et al., 2020; Smith et al., 2016). Adults with CF often feel that their illness is a burden on others and worry about the impact of their shortened life span, sexuality, and infertility on their close and intimate relationships (Macdonald et al., 2019; Mueller et al., 2020; Pakhale et al., 2015). Today, social media has assisted those with CF to feel less alone, however, this too has its drawbacks. For example, many adolescents and adults unfavourably compare their own CF journey to that of others and can lose valued connections when friends pass away (Macdonald et al., 2019; Mueller et al., 2020; Nutting & Amos, 2020). CF pulmonary exacerbations may worsen symptoms of anxiety and depression through several biopsychosocial mechanisms, for example, the negative impact of demoralization, stress, and inflammation (Quittner et al., 2016). There is evidence that a new diagnosis of CFRD and events such as hemoptysis may be followed by elevated symptoms of depression and anxiety (Hjelm et al, 2020; Quittner et al., 2014, 2015, 2016). The Memorial Symptom Assessment Scale (MSAS) is a validated measure of symptom burden with adults with CF demonstrating high symptom distress (Sawicki et al., 2008). Those with CF have complicated healthcare and other bureaucratic systems to navigate, for example, when trying to find funding for lifesaving and expensive medications, often whilst very ill and trying to lead “normal” lives, which can cause undue stress (Pakhale et al., 2014; Smith et al., 2016; Quittner et al., 2016). There are currently few studies on the prevalence of substance misuse in those with CF, although it is believed to be an issue (Maras et al., 2018; Mueller et al., 2020). More recent problems that impact the mental health of those with CF include, in the time of COVID, U.S. “Crisis Standards of Care” or rationing life preserving machines such as ventilators to those without chronic illness such as CF, which is demoralizing (Ladores, 2020). As well, mental health and neurocognitive symptoms have been experienced by nearly four percent of those on Trikafta, therefore they are faced with the dilemma

of whether to remain on this life saving medication and suffer the devastating side effects or discontinue use and see their health significantly decline (Bathgate & Barboa, 2021; Heo et al., 2021; May et al., 2021).

Depression and anxiety in persons with CF are associated with worse health related quality of life, lower lung function, severe chest pain, reduced body mass, poor adherence to treatment, poorer health outcomes, increased hospitalizations, substance use and mortality (Besier & Goldbeck, 2012; Cronly et al., 2019; Duff, 2015; Garcia et al., 2018; Maras et al., 2018; Mueller et al., 2020; Pakhale et al., 2015; Quittner et al., 2014, 2015, 2016; Smith et al., 2016). In the TIDES study the recommendation was made that, "given these high rates of psychological symptoms and their documented effects on disease management, including clinic attendance and adherence to prescribed treatments, annual screening of depression and anxiety for adolescents and adults with CF and parent caregivers is warranted" (Quittner et al., 2014, p. 1095). Several psychosocial interventions have been found to improve mental health with other life limiting medical conditions such as cancer and there is reason to believe that these interventions would also apply to persons with CF (Pakhale et al., 2015; Quittner et al., 2015; Smith et al., 2016). Yet, despite the clinical relevance, until recently there has been inadequate research in the field of CF into the most effective psychotherapeutic interventions to treat anxiety and depression (DrexelNow, 2019; Garcia et al., 2018; Pakhale et al., 2015; Quittner et al., 2015; Riekert et al., 2007). A 2014 Cochrane review of psychotherapeutic treatments for those with CF, including those focused on treatment adherence, emotional adaptation, health related quality of life, and reducing anxiety and depression, concluded that only a few had been evaluated specifically for those with CF and their caregivers (Goldbeck et al., 2014, 2015). The review and an audit, research,

and guideline update found that more studies on psychotherapeutic interventions with persons with CF were urgently needed (Goldbeck et al., 2014, 2015).

In response to the TIDES study and Cochrane review and update, the International Committee on Mental Health (ICMH) in Cystic Fibrosis: Cystic Fibrosis Foundation (CFF) and European Cystic Fibrosis Society (ECFS) was formed and developed 15 guideline consensus statements for screening and treating depression and anxiety specifically for CF (Quittner et al., 2015). There had been no CF guidelines for screening and psychotherapeutic interventions therefore the ICMH used existing guidelines for those with chronic illness to frame CF specific recommendations (Quittner et al., 2015). Amongst their recommendations: annual screening for depression and anxiety, utilizing the PHQ-9 (patient health questionnaire, the depression module which scores each of the nine DSM-V criteria) and GAD-7 (a seven-item instrument used to measure or assess the severity of generalized anxiety disorder). The utilization of the PHQ-9 and GAD-7 to monitor treatment response is also recommended; clinical assessment guidelines including in the instance of suicide risk; a collaborative stepped care model for clinical intervention in alignment with screening scores; evidence-based interventions such as cognitive behavioral therapy (CBT) or interpersonal therapy (IPT); and interventions to enhance coping skills, stress management training, and behavioural approaches to reduce the risk of distress for those undergoing medical procedures (Pakhale et al., 2015; Quittner et al., 2015; Smith et al., 2016). Since the ICMH guideline consensus statements recommending evidence-based practices, there has been an effort to find CF specific evidence-based counselling and psychotherapeutic practices, mostly utilizing qualitative and quantitative methodology, however, more recently with a participatory turn. Current examples of psychotherapeutic intervention trials include: 1) CF-CBT, the Mass General group is conducting a randomized controlled trial in adults in the United States

and a pilot of an e-health version in the Netherlands (Georgiopoulos, 2020); 2) Acceptance and commitment therapy (ACT) in adults with CF, a multicentre randomized trial by Virginia O'Hayer and colleagues (2021); 3) a randomized controlled trial of telehealth acceptance and commitment therapy (ACT) vs supportive therapy to prevent anxiety and depression (Hoppe et al., 2020); and 4) e-health CF-CBT, an internet - based program integrating a therapist guided online self-management module and in person or virtual sessions (Verkleij et al., 2021). Of these studies, trials three and four had markedly increased participatory involvement. For example, O'Hayer's ACT therapy vs supportive therapy involved persons with CF in the trial design whilst Verkleij et al.'s study (2021) was inclusive of those with CF in central roles, guiding project development (DrexelNow, 2019). Notably, Verkleij et al.'s study (2021), in partnership with those with CF, led to unique outcomes critically strengthening the program modules: decreasing the amount of text, eliminating jargon, highlighting key points visually and removing pictures of children as many individuals with CF struggle with infertility.

When persons with CF and their families are involved in coproducing improvement of care, they bring insights from their experience-based knowledge otherwise unseeable to physicians and other team members and with an increased likelihood to work for the target group (Macdonald et al., 2019; Sabadasa, 2014). Most agree that patient and public involvement (PPI) must be an essential component of clinical practice guidelines, which can only be considered trustworthy when they include patient voices, preferences and are in alignment with their needs (Armstrong & Bloom, 2017; Armstrong et al., 2018). When clinical practice guidelines are inclusive of patient voices, they are patient centric, and evidence based (Hempstead et al., 2020). Although clinical practice guidelines are considered the recognised standard in clinical care, stakeholders have not traditionally been part of guideline development (Armstrong et al., 2018; Macdonald et al., 2019).

The 2011 United States Institute of Medicine's Guidelines We Can Trust recommended that guideline developers include patients and the public in the development process as did the Guideline International Network's GIN-Public Toolkit recommendations (Armstrong & Bloom, 2017; Hempstead et al., 2020). Despite increasing awareness and support regarding PPI in guidelines, there remains a significant gap between standards and practice, with only 8% of 101 organizations in the United States implementing this process (Armstrong & Bloom, 2017). This situation is changing, as is evidenced by the promising work of the Cystic Fibrosis Foundation and others and evidence now questions the suitability of guidelines without PPI (Macdonald et al., 2019).

Since 2004 the CFF has included patient and families in guideline development, with the latter participating in all 28 CFF care guidelines (Hempstead et al., 2020). The CFF has called for the involvement of at least one person with CF and/or family member to sit on guideline committees to decide on recommendations, however, PPI involvement has evolved over time (Hempstead et al., 2020). In 2014, beginning with the Infection Prevention and Control guidelines, public comment has been elicited on draft guidelines (Hempstead et al., 2020). The CFF has implemented Community Voice, expanded in scope in 2017, a platform where individuals with CF and their families can partner with researchers and clinicians on issues that matter to them (Hempstead, 2020). The following is an example of the vast participatory turn in the CFF in PPI involvement in the development of clinical practice guidelines. To create the ICMH guideline consensus statements for screening and treating depression and anxiety one person with CF and family members were included on an expert panel to vote on consensus statements, after which the CFF sought public comment and international distribution (Quittner et al., 2015; Smith et al., 2016). Compare this with the development of the CFF CF Lung Transplant Referral Consensus

Guidelines, published in 2019. Here, the CFF engaged a focus group of lung transplant recipients with CF and their spouses, led by one psychiatrist and the adult with CF on the guideline committee. Together they developed CFF consensus guidelines on lung transplant referrals for individuals with CF (Hempstead, 2020; Ramos et al., 2019). The involvement of the focus group was vital in that it informed the guideline committee of previously unknown psychosocial factors with regard to transplant, for example, barriers to transplantation, such as experienced stigma associated with the need for transplantation (does the need for transplant reflect a failure in treatment adherence on the part of the transplant recipient?), and the need for social support during the transition to transplant (Hempstead, 2020; Ramos et al., 2019). The focus group helped to fill a gap in the CF-specific lung transplant literature importantly informing treatment teams of CF-specific patient needs related to lung transplantation (Hempstead, 2020; Ramos et al., 2019). In an article in the Journal of Participatory Medicine, Hempstead et al. (2020) stresses that the involvement of persons with CF and/or family members in the development of the CFF guidelines is essential to keep focused on the variation of experience in the CF community, on patient needs rather than clinician wants, on a meaningful exploration of questions and outcomes that have a direct impact on patients' day to day lives and ensuring that language used is understandable and experience near (Hempstead, 2020). Another advantage is veering into new areas of exploration which would not have been considered by clinician researchers but are relevant to those with CF (Hempstead, 2020). A patient's perspective:

> The best medical care is a partnership between patients, families, and clinicians. As a patient, there are a few important ways we can contribute to the guideline development process. While CF clinicians are no doubt experts in cystic fibrosis, we are the experts on where the 'rubber hits the road' in CF care. Having a voice and a vote ensures that

guidelines are feasible and more likely to be accepted by the wider CF community. Finally, there is the feeling of empowerment that comes with being treated as a colleague and not just a patient. The role of guidelines continues to grow as evidence-based medicine becomes the standard. Those guidelines inform the care we receive and are expected to adhere to. Coproduction of guidelines is vital to ensuring that patient wishes and needs are always at the centre of guideline development (Hempstead, 2020).

In the United States, there is a burgeoning area of research inquiry into how to improve the mental health of those with CF, through psychotherapeutic interventions and clinical guidelines (DrexelNow, 2019; Garcia et al., 2018; Hempstead, 2020; Pakhale et al., 2015; Quittner et al., 2015; Ramos et al., 2019). A participatory turn in CF-specific psychotherapeutic intervention studies is evident and enhanced patient and public involvement (PPI) in CF- specific guideline development is the standard of care, yielding rich results applicable to practice previously unattainable (Hempstead, 2020; Hoppe et al., 2020; Macdonald et al., 2019; Quittner et al., 2015; Ramos et al., 2019; Sabadosa & Batalden, 2014; Verkleij et al., 2021). This mirrors the movement away from the old paradigm of the paternalistic clinician and healthcare system to patient engagement in participatory health research as a key component in patient-centred care (Busetto et al., 2020; Carman et al., 2013; Friesen et al., 2019; Hoppe et al., 2020; Kazmerski et al., 2018; Kidd et al., 2017; Kramer-Golinkoff, 2014; White & Verhoef, 2005). Quality improvement projects for those with CF are expanding across the globe, “leaving no person with CF behind” (Hoppe et al., 2020, p.2230). This participatory turn also parallels the movement in psychiatry, which is undergoing significant change, seeking to involve those with lived experience in research (Friesen et al., 2019). It is reminiscent of the pioneering works of Minihan et al. (2004, 20011), Deegan (2005), Riecken et al. (2005) and Lorenz (2010) in their participatory projects with persons

with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities, mentioned earlier in this thesis.

In Canada there have been limited studies in CF and mental health and especially CF - specific psychotherapeutic interventions with adults. CF- specific guidelines in mental health are not original but have been adopted from the CFF by Cystic Fibrosis Canada (CF Canada), for example, the ICMH guideline consensus statements for screening and treating depression and anxiety (Cystic Fibrosis Canada, n.d). Whilst always seeking the input of the CF community, CF Canada which has a comparable mandate to the CFF, has now formalized this process in 2021 and is building a new research strategy seeking public priorities in research. This includes workshops and other participatory approaches including the opportunity to join Elevate, a program based on the CFF Community Voice (Cystic Fibrosis Canada, n.d). Top workshop research priorities decided upon in 2021 included: understanding mental health and emotional well-being at different stages (Cystic Fibrosis Canada, n.d). I shall briefly outline here the Canadian CF-specific studies in mental health and counselling, relevant to this thesis. Most of these utilize qualitative and quantitative methodologies with some incorporating participatory approaches.

Research into counselling practices with caregivers of children with CF and their offspring has yielded promising findings based upon the delivery of a cognitive-behavioural program, CF Chatters (Moola et al., 2016; Moola, 2019). Findings support the benefits of counselling with the CF community. They call for CF teams and researchers to re-examine best practice guidelines to include "opening new spaces for dialogue about the complex social lives, worlds and behaviours" of those with CF as a counterpoint to the "medicalization" or "excessive focus on health status and efforts to ward off disease and disability" of clinic appointments (Moola et al., 2016, pp.

2940, 2942). The importance of incorporating a counsellor into regular interdisciplinary CF care to assist throughout the various life stages and the need to educate health care teams on the need to broaden their repertoire of helpful therapeutic interventions was recommended (Moola et al., 2016). Macdonald et al. (2019) have also conducted enlightening research pointing to the folies of an adherence driven healthcare system, finding that CF health care providers and researchers miss the mark in terms of their understanding of adherence, with patients having an entirely different perspective: they do not relate to the word nonadherence but are rather working overtime to manage CF, work and have a normal life. They emphasize that clinical practice guidelines must be developed with the direct input of patients, otherwise their perspectives, needs and wants will be misrepresented (Macdonald et al., 2019). They suggest that care providers enter a collaborative dialogue with patients where treatment expectations are shared thereby leading to more beneficial individualized treatment plans (Macdonald et al., 2019). Pakhale and colleagues have been to my knowledge the most prolific in conducting research into CF and mental health in Canada (Balfour et al., 2014; Maras et al., 2018; Pakhale et al., 2014, 2015; Pakhale, Baron et al., 2016). Many studies are part of a larger research project entitled, “The Ottawa Cystic Fibrosis Treatment Knowledge and Adherence Program.” These studies explore various topics, including the relationship between CF knowledge and adherence, breathless catastrophizing, and its relationship to poorer quality of life, how adults living with CF understand treatment recommendations and the impact on adherence, the assessment of stigma in patients with CF as well as a cross-sectional study of the psychological needs of adults with CF (Balfour et al., 2014; Maras et al., 2018; Pakhale et al., 2014, 2015; Pakhale, Baron et al., 2016). In the latter study, based at the Adult CF clinic at The Ottawa Hospital, results indicate that 40 percent of participants were interested in talking about “worries, life stress, mood, adjustment to CF-related

issues/milestones, life transitions, and quality of life," amongst other concerns, if they had a psychologist (for the purposes of this study), embedded in their CF clinic team (Pakhale et al., 2015, p.7). There has been no follow up study. Pakhale and colleagues had employed participatory practices in select studies, for example, utilizing focus groups with CF patients and family members to help validate a Cystic Fibrosis Knowledge Scale, focus groups with CF patients and informal caregivers to identify key themes in understanding experienced stigma, and relying upon information gleaned from previous focus groups to inform psychological needs assessment items (Balfour et al., 2014; Pakhale et al., 2014, 2015). Pakhale and colleagues have also been involved in vital CBPAR utilizing The Bridge Model™ aimed at smoking cessation, battling addictions and homelessness among other matters (Charron et al., 2018; Pakhale, Kaur et al., 2016; Pakhale et al., 2018; Looyen & Bolton, 2019).

The case for a patient centred framework for counselling and psychotherapy for persons with a progressive and/or acquired non-visible illness/disability: cystic fibrosis is as follows: multiple studies have shown that persons with CF struggle with similar mental health, identity, and existential and spiritual issues as others with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities and have characteristics of living with CF which negatively impacts their mental health (Bathgate & Barboa, 2021; Berlin et al., 2005; Bone, 2017; Borschuk et al., 2016; Canda, 2001; Goldbeck et al., 2014, 2015; Heltshe et al., 2017; Heo et al., 2021; Hogg et al., 2006; Horky et al., 2017; Hjeln et al., 2020; Ladores, 2020; Langawai et al., 2020; Macdonald et al., 2019; Maras et al., 2018; May et al., 2021; Modi et al., 2010; Mueller et al., 2020, Nutting & Amos, 2020; Oliver et al., 2014; Pakhale et al., 2014, 2015; Quittner et al., 2014, 2015, 2016; Sawicki et al., 2008; Sharma et al., 2020; Smith et al., 2016; Trandel et al., 2019; Varilek & Isaacson, 2020). There is an abundance of evidence that persons with CF have a

two to three times higher rate of anxiety and depression then the general population, which impacts their physical health and at the extreme, the likelihood of mortality (Besier & Golbeck, 2012; Garcia et al., 2018; Maras et al., 2018; Mueller et al., 2020; Pakhale et al., 2015; Quittner et al., 2014; Smith et al., 2016). Since the TIDES study and Cochrane review and the ICMH guideline consensus statements for screening and treating depression and anxiety specifically for CF that followed, there has been a concerted push to find CF-specific psychotherapeutic interventions to ameliorate anxiety and depression in those with CF and positively impact their health-related quality of life. With the advent of Trikafta and other CFTR protein modulators, persons with CF are living longer and efforts have accelerated even further to address their psychosocial needs (DrexelNow, 2019; Garcia et al., 2018; Goldbeck et al., 2014, 2015; Hempstead, 2020; Pakhale et al., 2015; Quittner et al., 2014, 2015, 2016; Ramos et al., 2019).

Recent Canadian studies have found that persons with CF want counsellors embedded in their CF teams as a counterpoint to the medicalization of their appointments and to talk about many issues that concern them alongside anxiety and depression such as adjustment to CF-related issues/milestones (Moola et al., 2016; Pakhale et al., 2015). In another study the authors point to the discrepancy in the understanding of adherence between CF health care teams and persons with CF - non-adherence versus working overtime to manage CF – as an imperative to integrate the voices of those with CF in treatment planning and clinical practice guidelines (Macdonald et al., 2019). In the United States, several CF-specific evidence based psychotherapeutic trials are underway to test their efficacy with this population, however, what in their own words do persons with CF see as beneficial to them when they engage in counselling and psychotherapeutic practices (Georgiopoulos, 2020; Hoppe et al., 2020; O'Hayer, 2021; Verkleij et al., 2021)? Those with disabilities, disability theorists and researchers understand that psychotherapeutic interventions

and clinical practice guidelines must include end users of services in their conceptualization, design, and implementation, lest we risk clinicians wants obfuscating patient needs (Hempstead, 2020; Macdonald et al., 2019; Pakhale, Kaur et al., 2016; Pakhale et al., 2018).

Building upon the rich PAR findings of Deegan (2005), Riecken et al. (2005) and Lorenz (2010), the PHR findings of Minhan et al. (2004), the participatory turn in CF-related psychotherapeutic intervention studies, CFF and CF Canada participatory guidelines and research strategies, recent Canadian studies and most importantly listening closely to the voices of our patients at our Adult CF clinic, I embarked upon my research (Balfour et al., 2014; Busetto et al., 2020; Carman et al., 2013; Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Deegan, 2005; Friesen et al., 2019; Hempstead, 2020; Hoppe et al., 2020; Kazmerski et al., 2018; Kidd et al., 2017; Kramer-Golinkoff, 2014; Lorenz, 2010; Macdonald et al., 2019; Maras et al., 2018; Minihan et al., 2004; Moola et al., 2016; Pakhale et al., 2014, 2015; Quittner et al., 2016; Ramos et al., 2019; Reiken et al., 2005; Sabadosa & Batalden, 2014; Verkleij et al., 2021; White & Verhoef, 2005). My research question: What would constitute A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis? This study is part of the larger research project entitled, “The Ottawa Cystic Fibrosis Treatment Knowledge and Adherence Program,” and utilizes The Bridge Model, ™ a CBPAR approach of patient engagement, and the key principles of participatory action research inclusive of the four steps of PAR, which I will elaborate upon in my methodology chapter (Pakhale, Kaur et al., 2016; Pakhale et al., 2018). It is original in its scope in North America as it follows the participatory turn in CF and mental health and is inclusive of patients as co-researchers in every aspect, thereby filling a gap in the CF - specific mental health literature for fully utilizing PAR. As co-researchers, patients have been involved in every part of this study– from Topic Guide question

construction to co-facilitating focus groups to developing and revising the framework to the dissemination of results. We have developed A Patient-Centred Framework for Counselling and Psychotherapy by and for those with CF, privileging the voices of end users of services to create culturally informed ethical and evidence-based practice (Artman & Daniels, 2010; Chu et al., 2016; Cornish et al., 2008; Olkin, 2007; Pakhale, Kaur et al., 2016; Pakhale et al., 2018; Warnecke, 2017). In wholly utilizing PAR, this study stands in alignment with disability theorists and researchers (Balcazar et al., 2004, 2006; Lezzoni & Long-Bellil, 2012; Kidd & Kral, 2005; Moola et al., 2016; Olkin, 2007; Parkinson, 2006; Spong & Waters, 2015). Armstrong and colleagues advocate for guideline developers to create plain language products to facilitate guideline uptake in target groups and implementation within systems (Armstrong & Bloom, 2017; Armstrong et al., 2018). The result of our study is a plain language framework for counselling and psychotherapy for persons with CF – outlining preferred therapist attitudes, knowledge, and skills as well as a note to our CF clinic team – the latter of which developed organically as happens in a participatory action project. This study has also developed into a quality improvement project for our Adult Cystic Fibrosis clinic at the Ottawa Hospital. It has improved the way we intervene with all patients, helping us to better meet their mental health needs. In developing this framework, we have provided an opportunity for persons with CF to develop a sense of agency over matters of great import to them, which has reportedly been empowering. It behooves us to get it right, to listen carefully to the voices of those with CF so that counselling and psychotherapy are cogent and reflective of their expressed needs (Creswell et al., 2007).

Chapter 7: Methodology

This study is part of a larger research project entitled, “The Ottawa Cystic Fibrosis Treatment Knowledge and Adherence Program.” The Ottawa Health Science Network Research

Ethics Board approved this project (OHSN REB # 2011046-01H) as did the research Ethics Board at Saint-Paul University (Saint Paul University REB #1360.1/20) and all participants provided signed consent. Prior to signing the Participant Informed Consent Form (Appendix A) all participants were informed of the following: purpose of the study; the details of their participation; the risks and benefits of participating; voluntary participation and the right to withdraw from the study at any time; confidentiality; information regarding an honorarium; and who to contact regarding general questions, rights as participants or about ethical issues related to the study. Based on the research question, indicated in the introduction on pages seven and again on page 80 the methodology for this study utilizes The Bridge Model, ™ a CBPAR approach of patient engagement, and the key principles of participatory action research inclusive of the four steps of PAR (Pakhale, Kaur et al., 2016; Pakhale et al., 2018). CBPAR and PAR are mostly interchangeable research practices and will here forward be referred to as PAR. This study distinguishes itself from The Bridge Model™ only in that it explicitly uses the four steps of PAR – the cyclical spiral composed of multiple sequences of planning, action, observation, and reflection - to achieve its aims (Appendix B). The four steps of PAR will be further elaborated upon in this chapter.

PAR is grounded in a commitment to the democratization of research -everyone has a voice, everyone benefits and everyone has a role - and to the disability community rallying cry, “nothing about us without us” (Ashby, 2011; Balcazar et al., 2004, 2006; Borg et al., 2012; Kidd & Kral, 2005; Lezzoni & Long-Bellil, 2012; Minihan, 2004; Olkin, 2007, p.10; Pakhale, Kaur et al., 2016; Pakhale et al., 2018; Parkinson, 2006; Spong & Waters, 2015). The origins of PAR began in the early 19th century with the philosopher John Dewey, who considered participation the core of democracy, with PAR principles operationalized by his student B..R. Ambedkar, who studied

the discriminatory caste system in India. PAR was further developed by the social scientist Kurt Lewin who advocated for the democratic participation in research of people facing exploitation and Paulo Friere who promulgated a "liberationist ideology of the disempowered" (Benjamin-Thomas et al., 2018; Creswell et al., 2007; Friere, 201; Kidd & Kral, 2005, p. 188; Pakhale, Kaur et al., 2016; Pakhale et al., 2018). PAR is fundamentally a collaborative process between researchers and participants, often referred to as co-researchers, founded on the belief that meaningful change can only happen when persons impacted by a problem are integrally involved in the research to ameliorate it (Ashby, 2011; Benjamin-Thomas et al., 2018; Borg et al., 2012; Kidd & Kral, 2005; Minihan, 2004; Pakhale, Kaur et al., 2016; Pakhale et al., 2018). PAR researchers are concerned with facilitating voice, helping those impacted by a problem to tell *their* stories. This requires the de-centring of the researcher's voice by practicing self-reflection & creating safe, respectful, and collaborative spaces to enable stories to be told (Ashby, 2011; Borg et al, 2012; Kidd & Kral, 2005; Minihan et al., 2004). "The subject/object, sociopolitical, and role assumptions embedded in traditional research designs (and hence made invisible) are thus critically examined and reconstructed in PAR research" (Kidd & Kral, 2005, p. 189).

Persons with CF have asked for a voice regarding research about them and at CF clinic appointments, therefore PAR is well suited to their needs (Benjamin-Thomas et al., 2018; Cystic Fibrosis Canada, n.d; Cystic Fibrosis Foundation, n.d; Macdonald et al., 2019; Moola et al., 2016; Pakhale et al., 2015). A framework for counselling and psychotherapy created by and for them ensures that they have a voice in guidelines and policies that directly impact their CF care and quality of life (Macdonald et al., 2019; Moola et al., 2016; Pakhale et al., 2015, 2018; Pakhale, Kaur et al., 2016). The method of analysis for this study is IPA as delineated by Smith, Flowers, and Larkin (2012). Physical and mental health are the biggest areas of research within IPA, which

is "concerned with the detailed examination of personal lived experience, the meaning of experience to participants, and how participants make sense of that experience" (Smith, 2011, p. 9). Since our study focuses on the illness experience of those with CF, their experiences in counselling and psychotherapy, and matters of existential import to them, it is well suited to IPA (Smith, 2011). Questions in our Topic Guide (Appendix C), for example, "Can you speak about what it's like to live with CF day to day– a few aspects of your experience that you would like to share?" and "How has your illness impacted your sense of meaning and purpose in life?" are typical of IPA (Smith, 2011, p.9). While IPA also has its theoretical origins in hermeneutics and ideography, the analysis in this study is rooted in its phenomenological arm, at every turn trying to be "experience close" to co-researchers by referencing their words as they try to make sense of their lives (Chamberlain, 2011; Smith, 2011, p. 10). The marriage between PAR and IPA lies in this very juncture. It is our co-researchers' voices we are after, and this study takes great care both in the methodology and analysis to elevate and empower. The result is A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis which is informing the practice of our CF interdisciplinary team at The Ottawa Hospital. In the following pages I will elaborate upon both PAR and IPA as these have been developed in this study. The final portion of the methodology chapter will briefly outline the study questionnaires.

PAR has been applied by researchers in various fields, from counselling and community psychology to participatory health research. There is no definitive taxonomy although a shared set of principles and procedures do exist (Benjamin-Thomas et al., 2018; Creswell et al., 2007; Kidd & Kral, 2005; Smith, Bratini et al., 2010; Smith, Rosenzweig et al., 2010; Pakhale, Kaur et al., 2016; Pakhale et al., 2018). In the following pages this researcher will itemize the most common

elements of PAR followed by how this study has implemented them in the section: The Four Steps of PAR.

- PAR has a shared theoretical basis - the democratization of research. Reason & Bradbury (2001) describe PAR as follows: a "democratic, participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participative worldview (...). It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people (...)" (p.1);
- PAR is made up of three constructs: participation, action, and research which, broadly, represent a commitment to collaboratively address action or social transformation that benefits all partners;
- PAR is a spiral composed of multiple sequences of planning, action, observation, and reflection. It is a cyclical and iterative process therefore the exact details of the study will evolve through a collaborative and reflective process with co-researchers. Step One: Researchers and/or members of a community identify issues to address/begin planning. Step Two: Researchers and co-researchers develop a course of action to address the issues and begin to implement it. Step Three: Observation. Step Four: Reflection. Reflection may occur at various points in the study and may involve some or all of the following: 1) Personal reflection: the co-researchers reflect upon how their beliefs and values are reflected in the research and if the research has changed them; 2) Epistemological reflection: co-researchers consider the methodology. For example, is the methodology getting at what matters most to them? and 3) Participant reflection: participants critically reflect upon the

research & its implications. Informed Planning: The cycle continues until all are satisfied that a sufficient plan or product is in place to address a problem;

- PAR begins with the unique needs and challenges of a given community. It builds upon the strengths and resources within the community. Ideally, it is community members who request the initiation of a PAR project; however, the researcher may begin a project understanding that a problem exists from previous studies or clinical experience;
- PAR involves the participation of co-researchers in all aspects of a research study, from question construction to review and analysis to dissemination of findings, in alignment with their wishes, skills and knowledge. The means and mode of participation may vary, and participants may decide to engage or opt out and must be supported to do so. Training may be provided, for example, in facilitating focus groups and maintaining consent and confidentiality. Training may involve subjects such as group process and consensus building. PAR promotes co-learning and is an empowering process;
- Often the first task of the PAR researcher is to establish dialogue with the community to discuss the details of the project, consider the problem and further ascertain needs. This can be accomplished through focus group discussions, semi-structured interviews, or other modes of inquiry. Most PAR studies involve qualitative methodology or mixed methods;
- PAR involves a dialogic experience that privileges the perspective of the interviewee. In PAR research there is a general line of inquiry, however, the process is iterative, with the interviewer revising questioning as the interview unfolds.

Throughout the PAR process co-researchers are active in the development of the interview guide. A Topic Guide can be initially developed by the researcher and then revised by co-researchers, to ensure that it is representative of their needs and goals. Opportunities to debrief may enhance the interview process and experience;

- It is important beginning in the early stages of PAR to establish mutual respect and collaboration between researchers and co-researchers. Researchers need to continually work toward addressing power differentials and facilitating reciprocity within the research process. They may exhibit reflexivity by intentionally facilitating the sharing and negotiation of power, for example, being mindful of dominating discussions and adopting more of a supportive role**;**
- To make the PAR approach genuine, it must truly be enabling of multiple, critical voices and collaboration. Since PAR is focused on the privileging of many voices it is favourable to include individuals with a rich array of experiences, educational qualifications, socio economic status, knowledge, abilities and skills;
- Thematic analysis is well suited to PAR. Audio tapes and/or video transcripts are analyzed for themes, relevant to the topic being studied. In PAR co-researchers may be actively involved in data analysis and member checking - findings are reviewed with co-researchers to ensure both accuracy and relevance;
- There exist proposed practice guidelines for reporting PAR which include effectively conveying key elements of the project such as outcomes and/or emergent actions, and co-researchers' voices through the use of quotations, rich detailed descriptions, and reflections (which may include personal outcomes and the benefits and challenges of the project);

- Research findings must be formalized into a community action plan which has been derived from the local knowledge of co-researchers to effect real change in their lives. As is typical of a PAR project, there is a relevant and concrete result which might include policy, program development, guidelines or service interventions or improvements. Empowerment and consciousness raising may not be limited to co-researchers but may extend to institutions regarding the situation of persons seeking their help. Reflection is encouraged regarding the transformation accomplished in terms of what was achieved or not achieved both individually and as a community;
- Validity in PAR centres on triangulation and transactional validity, which can be achieved through member checking. Validity in PAR as it applies to this study will be elaborated upon in detail in the section: Step two of PAR (Adelman, 1993; Ashby, 2011; Baum et al., 2006; Benjamin-Thomas et al., 2018; Bergold & Thomas, 2012; Borg et al., 2012; Braun & Clarke, 2012; Caretta & Pérez, 2019; Cook, 2012; Creswell et al., 2007; Etowa et al., 2007; Friere, 2017; Khanlou & Peter, 2005; Kidd and Kral, 2005; Macdonald, 2012; Minihan et al., 2004; Pakhale, Kaur et al., 2016; Pakhale et al., 2018; Reason & Bradbury, 2001; Riecken et al., 2005; Smith, Bratini et al., 2010; Smith, Rozenzweig, et al., 2010; Stone & Priestly, 1996).

The Four Steps of PAR

7.1 Step One: Researchers and/or Members of a Community Identify Issues to Address/Begin Planning

Persons with CF face the following issues:

- A prevalence of mental health concerns such as anxiety and depression and other issues which, if not adequately treated, can adversely impact their physical health;
- Counsellors/psychotherapists and interdisciplinary team members not believing them or understanding the nuance of their experience due to the non-visible nature of their illness/disability. They can feel misunderstood and isolated;
- Counsellors/psychotherapists and interdisciplinary team members not having the necessary attitude knowledge and skills to attend to their mental health. They can feel these needs go unattended;
- Counsellors/psychotherapists and interdisciplinary team members talking at them with "expert" voices instead of collaborating with them in treatment planning. They can feel disempowered and marginalized;
- In summary, persons with CF struggle with anxiety and depression at a higher rate than the general population which can negatively impact their physical health. They can feel misunderstood and shut out in counselling and psychotherapy sessions, at CF clinic appts and within systems, when it comes to adequately understanding and addressing their mental health and treatment needs. While there is a participatory turn in CF-specific psychotherapeutic studies there is a gap for robust participatory action research in this area designed by and for those with CF in alignment with the disability slogan, "nothing about us without us," as well as for plain language guidelines even while it has been shown that these would facilitate uptake in target groups and implementation within systems (Armstrong & Bloom, 2017; Armstrong et al., 2018; Ashby, 2011, Bassler, 2014; Besier & Golbeck, 2012; Canda, 2001; Cronly et al., 2019; Davis, 2005; Duff, 2015; Garcia et al., 2018; Georgiopoulos, 2020; Heltshe et al., 2017; Hjelm et al, 2020; Hoppe et al., 2020;

Horky et al., 2017; Kidd & Kral, 2005; Langawai et al., 2020; Macdonald et al., 2019; Moola et al., 2016; Maras et al., 2018; Mueller et al., 2020; O'Hayer, 2021; Pakhale et al., 2015; Quittner et al., 2014, 2015, 2016; Reicken et al., 2005; Sharma et al., 2020; Smith et al., 2016; Trandel et al., 2019; Varilek & Isaacson, 2020, Verkleij et al., 2021).

7.2 Step Two: Researchers and co-researchers develop a course of action to address the issues and begin to implement it

Having identified the issues, the following course of action was developed and implemented. Only minor changes to the initial plan were necessary due to COVID 19:

Ethics Approval. This study is part of a larger research project entitled "The Ottawa Cystic Fibrosis Treatment Knowledge and Adherence Program," at The Ottawa Hospital with Dr. Smita Pakhale as principal investigator. An amendment to the larger research project was submitted to The Ottawa Hospital Science Network Research Board (OHSNRB) and approved (OHSN REB # 2011046-01H). As part of the application and approval process to OHSNRB this researcher completed the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics and obtained the TCPS 2: Core certificate. Once we had formal approval through OHSNRB an application was submitted to the Research Ethics Board at Saint-Paul University and accepted (Saint Paul University REB #1360.1/20).

Funding. This researcher was awarded funding through The Society for Pastoral Care and Counselling Research Grant, Saint-Paul University, which paid for key facets of this study, for example, co-researchers' honorariums.

Honorarium. An honorarium of $30 was offered to each co-researcher as appreciation for voluntarily choosing to participate in this research project. Honorariums were given out mostly via

e-transfer due to the pandemic. Four co-researchers asked that we donate their honorariums to charities of their choice.

Research Impartiality/Transparency. This PhD candidate is a member of The Ottawa Hospital Outpatient Adult Cystic Fibrosis Clinic interdisciplinary treatment team as a social worker and psychotherapist. To avoid conflict of interest the following measures were taken: our CF clinic nurse coordinator sent out all recruitment emails; this researcher participated in recruitment follow up where co-researchers had been seen in counselling and psychotherapy and completed treatment and where they had not been seen as yet; a research assistant was hired to participate in recruitment follow up where this researcher was seeing patients ongoing in counselling and psychotherapy; the same principle applied to focus group co-facilitation and the conduction of semi-structured interviews. As it happens all focus groups included co-researchers that were being seen ongoing for counselling and psychotherapy by this researcher, therefore they were co-facilitated only by co-researchers and the research assistant.

Sampling. A purposive representative sampling plan was utilized to select co-researchers for this project, with the intent that their makeup would represent others in their community. Inclusion Criteria was individuals 18 years of age and older, with CF. Recruitment continued for a period of three months until we had three focus groups comprised of six-seven individuals with CF at various phases of their disease process and human developmental stage: Group one: those with CFRD; Group two: those with CF aged 39 +; Group three: those with CF aged 18-29. It had been anticipated that there would be some overlap, for example, individuals with CFRD also fell in the 18-29 age range. This researcher chose to incorporate a cross section of persons with CF as there is evidence in the research literature that including diverse individuals with non-visible illness/disabilities adds richness to findings with commonalities discovered across groups lending

credence to outcomes (Bassler, 2009; Evans, 2017; Fitzgerald & Paterson, 1995; Gordon et al., 1998; Valeras, 2009, 2010); 19 co-researchers signed on and completed all the necessary documentation (Consent form, Socio-demographic Questionnaire, PHQ-9 and GAD-7) with only one leaving the study at the outset of their focus group after their daughter fell ill (a 95% retention rate). At the time, according to our CF clinic nurse coordinator, this number represented 15% of our overall CF population that attended clinic on a regular basis.

Recruitment. Three consecutive emails were sent out (approximately one month apart) with an initial and then revised recruitment letter (Appendix D) and consent form, by our nurse coordinator on her list serve, detailing the study to the CF patient population at The Ottawa Hospital Outpatient Adult Cystic Fibrosis Clinic. The first recruitment letter was designed by this researcher and the second was designed by three co-researchers, including the graphic, who had volunteered to "spruce it up." The original plan had been to also recruit for this study at CF clinic appointments, however, COVID 19 made this impossible as our vulnerable patient population had to mostly stay away from hospital unless struggling with an urgent health crisis. Patients interested in participating replied by email to our CF clinic nurse coordinator which she then forwarded to this researcher and either myself or the research assistant followed up. We thanked co-researchers by email for volunteering, asked them if they had questions and, if so, contacted them by telephone. Over the course of these communications, one co-researcher wanted to know "if they could have the questions in advance so they could think about the answers." Another co-researcher commented that they were looking forward to the focus group because "it's lonely sometimes as family (usually) and friends can not relate, see or feel." All were told that we would discuss further details when recruitment had been completed and we had adequate numbers to conduct the study. Co-researchers were asked to email in their consent. Due to COVID, consent forms were either

printed out, signed, and scanned back, e-signed and scanned back or, where co-researchers did not have access to a printer or scanner, the following written email consent was accepted, "I have read the consent form for this study, and I agree to participate." One of the co-researchers spoke Arabic, Hebrew and English and all communications and documentation were translated to Arabic to facilitate understanding. This researcher also spoke to them on the telephone regarding the study to ensure that they comprehended all the details prior to consenting to participate. This co-researcher confirmed on many occasions that they appreciated the effort to communicate with them in their principal language and that they fully understood. The recruitment process took approximately three months. When the patient-centred framework was in final draft format, a last recruitment email was sent out, by our nurse coordinator on her list serve to all CF patients at The Ottawa Hospital Outpatient Adult Cystic Fibrosis Clinic to request their feedback (Appendix D).

Participation. This study utilizes The Bridge Model, ™ a CBPAR approach of patient engagement, and the key principles of participatory action research inclusive of the four steps of PAR, in the development of a plain language Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Pakhale, Kaur et al., 2016; Pakhale et al., 2018). The idea of PAR is to stop telling stories *about* people and to facilitate the telling in *their* own words. As such, co-researchers have participated in every aspect of this study including: designing a recruitment email; participating in a co-facilitators' training session; participating in co-facilitator pre and post focus group preparatory meetings and debriefings; approving the research question and methodological design; revising a Focus Group Co-facilitator Cheat Sheet (Appendix E); designing a Participant Focus Group Cheat Sheet (Appendix E); revising the Topic Guide; co-facilitating all three focus groups; developing and revising the Patient-Centred Framework for Counselling and Psychotherapy with Persons with a

Non-Visible Illness/Disability: Cystic Fibrosis; and disseminating the results. Research updates were sent out via email to coincide with significant phases of the project, for example, once recruitment had been completed, to request volunteers to co-facilitate focus groups and to inform co-researchers of next steps and important details of the study. Communication was ongoing with co-researchers variously by email, telephone, or MS Teams, a confidential virtual platform approved by The Ottawa Hospital. Verbal consent to continue in the study was obtained and noted at each phase of the project. As example, once we had completed recruitment a mass email was sent out to co-researchers, all of whom had given their permission to share their email address with one another. The email read in part, "Thank you for volunteering to participate in this study! As this is a participatory study, our aim is to engage everyone as equal partners. As such we are seeking volunteers among you who would like to co-facilitate the focus groups and possibly conduct some of the semi-structured interviews." Four co-researchers volunteered immediately to co-facilitate focus groups with one later "jumping on board" and one volunteering as "back up." All reiterated that they understood the details of volunteering to co-facilitate a focus group, once explained, and consented to do so. All co-researchers were made aware of the terms of participation in this study by reading and signing the participant informed consent form inclusive of their voluntary participation and the option to leave the study at any time with no effect to their medical care, education or other services to which they were entitled or were receiving outside the study.

Focus groups. A focus group format has been used in this study to elicit a range of views, in depth discussions, the feeling of a collective experience, and a sense of empowerment (Owen, 2001; Tee, 2004). Great attention was paid to creating safe and collaborative spaces and in providing the necessary accommodations, as these conditions are ideal for sharing and learning,

particularly when working with vulnerable populations (Nordentoft & Kappel, 2011; Owen, 2001; Read & Maslin-Prothero, 2011; Tee & Lathlean, 2004). To ensure process transparency, discussions were had with each focus group regarding the purpose of the study, PAR, limits to confidentiality, and creating group safety amongst other vital subjects (Bond, 2004; Owen, 2001; Read & Maslin-Prothero, 2011; Tee & Lathlean, 2004). A Topic Guide was employed to guide discussions with room for flexibility in alignment with the needs of co-researchers and the larger group. All focus groups were conducted on MS Teams, a confidential video conferencing platform approved by The Ottawa Hospital. This was in conformance with infection control protocols in accordance with the Cystic Fibrosis Foundation Guidelines: 2013 update (Cystic Fibrosis Canada, 2018). Prior to focus groups beginning, training materials for focus groups were obtained from The Bridge™ inclusive of a Focus Group Co-facilitator Cheat Sheet, which was revised by co-facilitators in this study to fit the needs of our CF community. This researcher and our research assistant also met with a professor at Carleton University School of Social Work who teaches the compulsory Group Work course and gave us relevant articles to read and a brief tutorial on focus groups. A focus group co-facilitator meeting was held to introduce co-researchers to one another, ask and answer questions, review and approve methodology for this project, review and revise relevant documents such as the Topic Guide and the Focus Group Co-Facilitator Cheat Sheet, and overall provide focus group co-facilitator training. The purpose of focus groups, golden rules of ethical research, steps to conduct a focus group as well as Do's and Don't's and potentially difficult situations (group dynamics) were discussed as preparation. A Focus Group Participant Cheat Sheet was developed at the behest of co-facilitators. The meeting was held on MS teams and was organized by our research assistant to prevent a conflict of interest as some co-facilitators were engaged in ongoing counselling and psychotherapy with this researcher. Our research assistant

sent out an email in preparation for the co-facilitator meeting with the following attachments: meeting agenda (revised in part by co-facilitators prior to the meeting), the study's Topic Guide (initial format), and The Focus Group Co-Facilitator Cheat Sheet (initial format). Co-Facilitators were then assigned their respective groups in accordance with their phase of the disease process and human developmental stage: Group one: those with CFRD; Group two: those with CF aged 39 +; Group three: those with CF aged 18-29 (as outlined above). Once they were assigned, this researcher and our research assistant contacted all co-researchers via email to organize the groups (options for dates and times were provided in the body of the email)-this was requested by the co-facilitators who had been given the opportunity to do so themselves. Co-facilitators were asked for their input on all emails sent to their focus groups. A participant call log was designed and organized by our research assistant. Focus groups were organized for the following dates and times: focus group one September 29, 2020, at 6:30; focus group two October 5, 2020, at 5:30; and focus group three October 8, 2020, at 6:30. Dates and times are significant as focus groups occurred six months after the COVID 19 pandemic began and in the evenings which can be difficult for those with CF due to fatigue. This subject will be elaborated upon in the chapter on findings in this thesis. An email was sent out to each of the three groups, updating them on the project, introducing them to their co- facilitators (who wrote a brief summary about themselves), and requesting that they read the Focus Group Participant Cheat Sheet (attached) and complete the Socio-demographic Questionnaire (attached) and PHQ-9 and GAD-7 (attached) at least 48 hours prior to their focus group. The idea of pre-distributing the Focus Group Participant Cheat Sheet had been "to get everyone on the same page in terms of focus group purpose and to emphasize ground rules to create an atmosphere of safety and trust." Regarding the Socio-demographic Questionnaire (Appendix F) and PHQ-9 and GAD-7 (Appendix G) this researcher wrote, "This is

for the purposes of the study and completely confidential between you and me. It will give me a better sense of the rich diversity of our group. We can complete these together either by phone or on MS Teams." A later email was sent asking co-researchers if they wanted the Topic Guide questions in advance of the focus group and with instructions for MS Teams. All but two of the co-researchers requested the Topic Guide questions, which were sent 48 hours in advance. This researcher met with each co-researcher to ensure that they were able to download the MS Teams App and sign on and answer any research related questions. One of our co-researchers was offered an English - Arabic interpreter for the focus group and we were able to procure the services of MCIS Language Solutions, the interpretation services utilized by The Ottawa Hospital and bound by their confidentiality agreement. At the behest of the co-researcher, we were able to secure the services of the interpreter that we had used previously at their CF clinic appointments and with whom they had felt "familiar." This co-researcher asked to attend the focus group by telephone with the interpreter attending on MS Teams at which point this researcher contacted the interpreter to ensure that she was able to download and sign on to the App. All in focus group one were advised by email that an interpreter would be joining them, that she was bound by confidentiality through her TOH contract, and encouraged to ask any questions. Groups one and three were co-facilitated by two co-researchers (with our research assistant as back up, should a co-facilitator opt out for any reason) and group two was co-facilitated by a co- researcher and our research assistant. All co-facilitators met in preparatory meetings with our research assistant before their assigned focus group and some met for a debrief afterward – all on MS Teams. Groups one through three were all sent the following communication prior to meeting: "Should anyone want to reach me during or after the focus group you may reach me as usual through my TOH email: rleibovitch@toh.ca. You may also reach out to your co-facilitators or our research assistant

(contact information withheld here for the purposes of confidentiality).” At the outset of each group, co-facilitators had organized ice breaking exercises and went over “steps to conduct a focus group” items one through nine (going over ground rules) on The Focus Group Co-Facilitator Cheat Sheet - which were also in the Focus Group Participant Cheat Sheet, sent out ahead of time. Topic Guide questions were then asked, with co-facilitators sharing responsibilities as previously agreed. Most decided to divide the questions by topic area with the other paying close attention to group dynamics and intervening as necessary, for example, if one co-researcher was dominating the discussion. All co-facilitators understood that, while they had volunteered to facilitate the groups, we also wanted to hear their answers to the Topic Guide questions. Most found this “tricky” at first to both facilitate and respond to questions but acclimated as the groups progressed. One of the co-researchers in advance of her focus group, had explained that she had some learning difficulties and asked that she be able to write her answers down and that co-facilitators pay close attention to the “raise hands” button, which was respected. Another research update was sent via email to all co-researchers after the last focus group to thank them for their participation, express gratitude to our co-facilitators and our research assistant, explain next steps – some may be contacted to participate in a semi-structured interview - and to organize payment of the honorarium. Many had asked (as above) to remain in touch with one another and this researcher obtained their consent to share their emails if they chose to do so. One co-researcher opted out stating, “Regretfully, I'm going to have to decline sharing my e-mail contact information. While waiting for transplant 10 years ago, I befriended dozens of CFers. Sadly, all but one has passed away. I hope this makes sense.” Of course, their wishes were respected.

Semi-structured interviews. Semi-structured interviews were conducted to get a rich picture of the personal experience of individual co-researchers that they might not share in a focus

group setting. Each semi-structured interview utilized the Topic Guide. While important to be consistent between co-researchers, flexibility was permitted to allow for sufficient and meaningful input. Two participants, those with the highest and lowest GAD-7 scores per focus group were selected for interview. The reason for this selection was the diversity of experience, needs and opinions that this might yield. As well, where commonalities amongst co-researchers with disparate scores occurred this lends a validity and richness to results. Each co-researcher was notified by email that they had been selected for an interview and then asked if they consented to participate. This was followed by a telephone call to answer any questions. Their verbal consent was noted. The semi-structured interviews were conducted by this researcher and our research assistant. Again, where a co-researcher was being seen ongoing by this researcher in counselling and psychotherapy our research assistant notified them, requested their verbal consent to be interviewed, answered any questions, and conducted the interview. This researcher conducted all other semi-structured interviews. All semi-structured interviews took place on Microsoft Teams. One semi-structured interview was held with each co-researcher for a period of 60-90 minutes, depending upon their needs and duration of responses.

Topic Guide. The Topic Guide was initially designed by this researcher but revised significantly by co- facilitators at the focus group co-facilitators' meeting. Co-researchers were also encouraged to offer feedback on the Topic Guide and their views were integrated. The outcome was that the Topic Guide became "less theoretical and wordy." For example, fewer questions were asked per the three key subject areas: problem identification/needs analysis; questions regarding necessary counsellor/psychotherapist attitudes, knowledge, skills and what would constitute the framework; and reflection questions on the methodology used in this research. Twelve questions were decided upon. Formatting also changed to make questions clearer. For

example, Question seven changed from "If you have reached out to a counsellor/therapist within or outside of the hospital system what experiences stand out for you as helpful or unhelpful?" to "If you have reached out to a counsellor/therapist within or outside of the hospital system what experiences stand out for you that you would like to share: a) Please give examples of any helpful experiences; b) Please give examples of any unhelpful experiences." The result was a more robust Topic Guide, having been designed by and for our co-researchers, that yielded a framework better in alignment with their needs.

Data Collection and Confidentiality. Following the Glaserian dictum all is data focus groups, semi-structured interviews, the focus group co-facilitator meeting, focus group preparatory and debrief sessions, as well as co-researcher and key stakeholder feedback regarding the study and framework have been recorded or noted and securely saved (Glaser, 2004). All focus group and semi-structured interviews were recorded on Microsoft Teams, and we employed a backup recording device as a precautionary measure. The MS Teams transcription service was also utilized; however, transcripts were inaccurate, and this researcher reviewed all recordings and revised transcripts until they corresponded. Minutes were taken at the focus group co-facilitator meeting, and in other instances, for example, debrief sessions, this researcher or our research assistant took more informal notes. At key junctures of the research process co-researchers and, where appropriate, key stakeholders were informed of next steps, usually by email. Feedback regarding the framework occurred either by email, telephone, or MS Teams. All transcriptions, recordings, notes and emails have been kept confidential, stored in a locked filing cabinet at the researcher's home office due to COVID 19. All co-researchers were made aware of the terms of confidentiality by reading and signing the participant informed consent form inclusive of refraining from using names during the focus groups and semi-structured interviews, the secured

storage of data and the use of de-identified data for research purposes. Our interpreter abided by the terms of confidentiality as set out by her employment contract with The Ottawa Hospital. In some instances, key stakeholders have agreed by email or verbally to share the content of their feedback (with or without identifying information) for research purposes, and should this study be published.

Method of Analysis. The method of analysis for this study is IPA as delineated by Smith, Flowers, and Larkin (2012). IPA is committed to a detailed analysis and understanding of specific experiential phenomena, for example, a non-visible illness/disability, and how it has been understood and made meaning of, from the perspective of persons, for example, those with CF. It is an iterative and cyclical process which moves through several stages and levels of abstraction as follows: 1) reading and rereading transcripts to gain a familiarity with the data; 2) initial noting/exploratory comments focused on three elements: a) descriptive comments (for example, key words, objects or experiences), b) linguistic comments (for example, laughter, word repetition, degree of articulacy), and c) conceptual comments (overarching understandings of what is being discussed); 3) developing emergent themes, based on exploratory comments; 4) developing super-ordinate themes, based on grouping emergent themes together; 5) moving from one semi-structured interview to the next and one focus group to the next to look at patterns; and 6) creating tables that include emergent themes and their corresponding super-ordinate (Smith et al., 2012). In section one of the chapter on findings (focus group vertical anlysis), this researcher will describe the characteristics of each of the three focus groups: general characteristics of co-researchers, socio-demographic details, PHQ-9/GAD-7 scores, and the dynamics unique to each group. This will be followed by an in-depth analysis of the super-ordinate themes, subsets, and key emergent themes for each group with quotes highlighting co-researchers' phenomenological experience. A

summary reflection will follow. In section two (focus group horizontal anlysis), this researcher will analyze findings across focus groups, underscoring commonalities and differences, again referencing the super-ordinate themes, subsets and emergent themes alongside co-researchers' own words. A similar process will be followed for the semi-structured interviews. In section one (semi-structured interviews vertical anlysis), after a brief introduction of key characteristics, this researcher will undertake an analysis of each of the six semi-structured interviews concentrating on what co-researchers have expounded upon. This will avoid repetition (from the focus group analysis) and add a richness to findings. Co-researcher's accounts will be presented in a narrative format to render their experience more intimately. In section two (semi-structured interviews horizontal analysis), this researcher will analyze findings across semi-structured interviews, emphasizing commonalities and differences amongst co-researchers, again referencing the super-ordinate themes, subsets, and emergent themes. Group dynamics will be described for each focus group. The analysis of focus group dynamics is integral to a fuller understanding of findings because it provides context, and insight into the struggles of participants (Farnsworth & Boon, 2010). Focus groups are useful in that group interactions bring to light the valuable lived experience of participants which would be less accessible in a one-to-one interview format (Farnsworth & Boon, 2010; Morgan, 1997). Individuals are influenced by one another, and this has an impact on what is shared and what is said. The focus group becomes a world within itself and can become "unexpectedly therapeutic," a safe setting to express oneself (Farnsworth & Boon, 2010, p. 213). As well the focus group can be a social frame, a place where participants project their issues, their anxieties and needs into the group setting (Farnsworth & Boon, 2010; Goffman, 1988). Whilst group development can be characterized by five stages progressing over a succession of meetings - forming (familiarizing), storming (the group encounters difficulties),

norming (developing cohesion), performing (accomplishing tasks) and adjourning (closure)- a focus group must move through these stages in one session, culminating at times in challenging group dynamics (Owen, 2001; Tuckman & Jensen, 2010). There are many ways to analyze group dynamics –structural, interactional, psychodynamic and process analyses – and this researcher has borrowed from some of these as well as existential theory to shed light on the focus groups in this study (Berne, 1964/2016; Fitzgerald & Paterson, 1995; Nouwen, 2021; Owen, 2001; Pachankis, 2007; Sbarby et al., 2019; Tuckman & Jensen, 2010; Varilek & Isaacson, 2020).

Validity. Validity in PAR centres on triangulation and transactional validity, which can be achieved through member checking. Triangulation is threefold: multiple perspectives, face validity to participants (the extent to which the project is viewed as covering the concept it purports to measure) and catalytic validity (the extent to which the participatory process catalyzes elements for change) (Baum et al., 2006; Bergold & Thomas, 2012; Caretta & Pérez, 2019; Cook, 2012; Kidd & Kral, 2005; Macdonald, 2012; Reason & Bradbury, 2001; Smith, Rosenzweig, et al., 2010). Triangulation in this study has been arrived at as follows: Multiple perspectives were achieved by creating three diverse focus groups representing different phases of their disease process and human developmental stage (CFRD; CF age 39+; CF ages18-30). Co-researchers also differed within and between focus groups on PHQ-9/GAD-7 scores and socio- demographic characteristics inclusive of gender identity, age, age at CF diagnosis, living status, relationship status, employment status, education and experience in counselling and psychotherapy. Face validity was established by co-researchers when answering question 10, designed for this purpose (epistemological reflection), in the Topic Guide. Catalytic validity is reflected in the feedback of both co-researchers and key stakeholders acknowledging an improvement in the way we address mental health care at our Outpatient Adult Cystic Fibrosis Clinic as a result of the framework

developed in this study: A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis. Finally, Transactional validity was established by co-researchers and stakeholders when they checked the framework for accuracy and resonance with their experience and their feedback was incorporated into sequential drafts (Caretta & Pérez, 2019). According to Smith et al. (2012) validity in IPA can be accomplished by following Yardley's (2000) four broad principles for assessing the quality of qualitative research- sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance - as well as the independent audit as put forward by Yin (1989). In this study: sensitivity to context and commitment and rigour have been achieved by purposive sampling, conducting quality interviews evidenced by co-researchers producing thick descriptions of their experience, and a rigorous analysis supported by verbatim quotes to support arguments; transparency has been demonstrated in this methodology chapter in the detailed description of this study, and coherence is shown in the fit between PAR and its theoretical underpinnings, the democratization of research; impact and importance has been attained in telling the reader something that is useful, for example, the expressed needs and preferences of those with CF in the attitude, knowledge and skills of their counsellors/psychotherapists and CF interdisciplinary team. Finally, the independent audit has been accomplished by this researcher's thesis director checking throughout that the analysis has validity in relation to the text being examined (Smith et al., 2012).

Ethical considerations and risks of this study. Ethical considerations of this study have included: 1) this researcher's apparently able-body and the co-researchers' apparently dis-abled bodies, which could have set up a hierarchical structure mirroring that of disabled persons in society; and 2) the phenomenon of othering, or the unintentional reinforcement of feeling marginalized by virtue of being chosen subjects of a study. To offset both characterizations, this

researcher has aimed to equalize power relationships, by creating safe and collaborative spaces and by including persons with CF as co-researchers in every aspect of this study (Riecken et al. 2005); Risks of this study have included: 1) co-researchers feeling exposed if they share information during focus groups that is more personal and emotionally charged than intended. In this instance, protective measures were put in place, such as opportunities for participants to debrief one on one post focus group session (Tee & Lathlean, 2004); and 2) co-researchers feeling vulnerable due to lack of familiarity with process or personal expectations. To protect co-researchers, process consent was employed: informed consent was obtained ongoing and not only as a one-time endeavor. For example, co-researchers learned about the details of each stage of the study and were given the opportunity to opt in or opt out according to preference (Bond, 2004; Nordentoft & Kappel, 2011; Owen, 2001; Read & Maslin-Prothero, 2011; Tee & Lathlean, 2004).

7.3 Steps Three and Four: Observation and Reflection

Steps three and four of this PAR project involved sharing the draft of the Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis with key stakeholders at three intervals (cycles) -after the analysis of the three focus groups, after the analysis of the six semi-structured interviews, and after the final draft had been approved– integrating their feedback and noting observations regarding any meaningful changes to how we address mental health at our CF clinic. Stakeholders at the first interval (cycle) included our 18 co-researchers, four respirologists as well as our CF clinic nurse coordinator. Stakeholders at the second interval (cycle) included our 18 co-researchers, four respirologists, our CF clinic nurse coordinator as well as other members of the interdisciplinary team, for example, our CFRD nurse, our dietician, and our psychiatrist. Over the course of the first and second cycles, co-researchers extensively reviewed and revised the framework ensuring that it was in alignment

with their needs, values, and goals for the project and then that we had integrated the feedback of interdisciplinary team members to their satisfaction. This process continued until we had a final draft framework that all agreed upon. Unanticipated aspects of the framework had developed during the semi-structured interviews and focus groups. For example, despite Topic Guide questions focused solely on the attitudes, knowledge and skills of counsellors and psychotherapists co-researchers wanted to also talk about their expectations regarding how mental health is addressed by their interdisciplinary CF clinic team. This resulted in the section in the framework entitled, "A note to our CF clinic team." Similarly, key areas of the framework evolved as we received stakeholder feedback. At the first cycle our CF clinic nurse coordinator was curious to know what patients felt their responsibilities were in seeking counselling and psychotherapy help and at CF clinic appointments regarding their mental health (posited to co-researchers by email). As a result, the section entitled, "Patient role" was developed with input and revisions from most co-researchers. An additional modification of the framework occurred as the result of feedback from another member of our interdisciplinary CF clinic team who expressed the following:

> It is clear that patients want more of a focus on mental health, and coping strategies, as part of their care plan…. unfortunately, I lack the training and experience in this area ….and instinctively shy away from asking probing questions about mental health.

To provide some guidance, co-researchers "built-in" specific suggestions for mental health related questions to the framework. As we cycled through the various iterations of the framework co-researchers were asked if they had observed a change in their mental health care at CF clinic appointments since its dissemination. As example, one co-researcher responded that they had noticed "more of an openness to mental health/more of a collaborative atmosphere." Interdisciplinary CF team members were asked their general impressions of the framework and if

it had impacted their practice with patients. As example, our CF nurse coordinator responded, "Well, you can let them know that I'm very happy that they have had direct input into their mental health care and that I've read it and completely get where they are coming from." The third interval of the project included disseminating the final draft of the framework to all patients at the Ottawa Hospital Cystic Fibrosis Clinic and eliciting and integrating their feedback with their consent. All co-researchers then approved of the changes. In total 30 (n=30) stakeholders (CF co-researchers, CF clinic patients, and interdisciplinary team members) developed and agreed upon the framework. The result is a robust plain language Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H) that we hope will not only enhance the mental health services that we provide at our clinic but that will be beneficial to other CF clinics across North America. Further discussion of the findings of this research will be elaborated upon in the following chapter.

7. 4 Questionnaires

Socio-demographic Questionnaire (Appendix F)

The Socio-demographic Questionnaire collected data on the following key variables to assign co-researchers to one of three focus groups, provide a rich description of our co-researchers and potentially identify trends within and between groups: gender identity, age, age at CF diagnosis, language, residence, living status, relationship status, employment status, education, and phase of their disease process and human developmental stage (CFRD; CF age 39+; CF ages18-30). Two questions at the end of the Socio-demographic Questionnaire ask co-researchers whether they identify as someone with a non-visible illness/disability and whether they have had previous experience as a client/patient in counselling and psychotherapy, after which we ask them to elaborate. Like many aspects to this participatory action study, the Socio-demographic

Questionnaire was initially designed by this researcher and revised in concert with our co-researchers.

Patient Health Questionnaire (PHQ-9) (Appendix G)

The PHQ-9 is an instrument used for screening, diagnosing, and monitoring the severity of depression useful in primary care settings. Questions may be asked in the context of an interview format or as a self report measure. It is a nine-item questionnaire which incorporates DSM-V depression diagnostic criteria. The tool rates the symptoms of depression as well as their severity over the last two-week period. Question nine on the PHQ-9 screens for the presence and duration of suicide ideation and if there is an affirmative answer the protocol is to follow up with The Columbia Suicide Severity Rating Scale (C-SSRS) (please see description below). A follow up question on the PHQ-9 measures the degree to which depressive symptoms affect level of functioning. In this study a plan was developed to contact any co-researcher who might score affirmatively to the PHQ-9, question nine, and follow up with a C-SSRS assessment regarding suicidality and possible referral to psychiatry or their family doctor for ongoing monitoring.

> The PHQ-9 is advantageous for several reasons: 1) it is based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV); 2) it is increasingly used across patient groups in research and health care settings; 3) it is easy to score; and 4) it is half the length of the Center for Epidemiological Studies Depression Scale (CES-D) but has comparable sensitivity and specificity (Pakhale et al., 2015, p. 9).

Generalized Anxiety Disorder (GAD-7) Assessment form (Appendix G)

The GAD-7 is a seven-item instrument that uses some of the DSM-V criteria for GAD (General Anxiety Disorder) to identify probable cases of GAD along with measuring anxiety symptom severity. It was modeled after the PHQ9 to be used quickly and effectively within a

primary care setting. Questions may be asked in the context of an interview format or as a self report measure. The tool rates the symptoms of anxiety as well as their severity over the last two-week period. A follow up question on the GAD-7 measures the degree to which anxiety symptoms affect level of functioning.

> The GAD-7 is routinely used in health care settings and has been found to have adequate psychometric properties, with an excellent internal consistency ($\alpha = 0.92$), good test-retest reliability ($r = 0.83$), and convergent validity with other validated anxiety scales such as the Beck Anxiety Inventory ($r = 0.72$) (Pakhale et al., 2015, p. 4).

The PHQ-9 and GAD-7 are self-report measures of mood that have undergone rigorous psychometric testing; however, the limitation is that they are not as comprehensive and reliable as a diagnostic interview. Co-researchers' PHQ-9 and GAD-7 scores were noted and informed study practices, for example, co-facilitator training was designed with the needs of vulnerable co-researchers in mind. Whilst both the PHQ-9 and GAD-7 have very high sensitivity and specificity scores, this researcher chose the GAD-7 over the PHQ-9 to select co-researchers for semi-structured interviews as the latter includes somatic items (questions three, four & five) which can increase and therefore obfuscate depression scores in persons with chronic illness (Nan et al., 2012; Pakhale et al., 2015; Quon et al., 2015).

The Columbia Suicide Severity Rating Scale (C-SSRS) (Appendix I)

There are four versions of the C-SSRS used in clinical practice and healthcare settings. Questions may be asked in the context of an interview format or as a self report measure. The two versions utilized in this study are the Risk Assessment Page and the Screener version for Outpateint/Ambulatory care, typically used at The Ottawa Hospital. The C-SSRS measures four constructs: a) the severity and b) intensity of ideation, c) behavior and d) lethality amongst other

factors. The purposee of the C-SSRS Risk Assessment Page is to help determine an individual's immediate risk of suicide. It looks at risks for suicide, for example, past suicidal and self-injurious behavior, and at protective factors, for example, responsibility to family or others; living with family. The C-SSRS Screener version is a shortened version of the full form (three to six items), which is used for the intial triage. The Suicide Intervention Check List has also been included in Appendix I as it is the third tier used at The Ottawa Hosiptal to guide intervention, for example, it provides guidance on risk assessment and management, prevention and referral to resources. All three measures were used by this researcher in this study where there was an affirmative asnswer to PHQ-9 question nine, beginning with the Screener version for Outpateint/Ambulatory care followed by the C-SSRS Risk Assessment Page and Suicide Intervention Check List to ensure accuracy (Posner et al., 2011).

Chapter 8: Findings

This portion of the thesis presents the findings of the research, that is, the superordinate themes, subsets and emergent themes which arose from the IPA. Emergent themes (in the focus group analysis) and super-ordinate themes (in the semi-structured interview analysis) are referenced numerically in parentheses alongside quotes and then in the Notes section of this thesis. Throughout the presentation of findings, the focus will be to call attention to the collective and individual experiences of those living with CF/CFRD as it relates to each of the following super-ordinate themes:

- 1. Experience living with CF (RD)[4] day to day;

[4] Throughout the findings chapter CFRD refers to cystic fibrosis related diabetes. CF (RD), with RD in parenthesis, is employed as an inclusive nomenclature when referencing super-ordinate themes across focus groups, where there are persons in a focus group that have both cystic fibrosis and/or cystic fibrosis related diabetes, and where a co-researcher has both illnesses and has specifically referenced this fact in the interview process. Where a co-researcher is being

- 2. Psychological impact of CF (RD);
- 3. CF (RD) as a non-visible illness/disability;
- 4. CF (RD) and sense of self/identity;
- 5. CF (RD) positive aspects and meaning and purpose in life;
- 6. Observations and recommendations;
- 7. Counselling and psychotherapy experiences;
- 8. Feedback and suggestions re: PAR methodology.

Super-ordinate themes are consistent across focus groups and semi-structured interviews; however, super-ordinate themes may contain subsets, which encapsulate and further pull together related emergent themes. For example, across the three focus groups for the super-ordinate theme "Experience living with CF (RD) day to day" there are fully nine subsets some consistently and others variously across groups: symptoms and treatments; interpersonal relationships; early and late diagnosis; impact on career; CF as spectrum; CF can be a dark disease; CF and the impact of COVID; Trikafta (this magic pill); and CF camp. Across the six semi-structured interviews for the super-ordinate theme "Experience living with CF (RD) day to day" there are seven subsets: symptoms and treatments; interpersonal relationships; impact on career; CF as spectrum; disability/illness and healthcare bureaucracy; significant cognitive impact; and existential responsibility. This reflects the nuance made possible by IPA. Please see Appendices J and K for

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investigated for both illnesses but does not have a confirmed diagnosis super-ordnate theme 6 also has the nomenclature CF (RD) as they are being followed by both CF and CFRD interdisciplinary team members. Many times, even though a co-researcher has CF (RD) they will only refer to CF and this too has been respected throughout the thesis. As the nomenclature CF is employed more broadly it is also applied here following the language of co-reserchers: CF community, CF patients, CF teams, CF clinic, and in the title of this thesis. Finally, most persons with CF (RD) are diagnosed with CF in childhood whereas CFRD is acquired. For this reason, when referring to co-researchers in their childhood the nomemclature CF is applied, following their language.

a visual representation of super-ordinate themes with subsets across the three focus groups and six semi-structured interviews.

The Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis had initially been developed based on the following super-ordinate themes and subsets: 6. Observations and recommendations for CF(RD): a) counsellors/psychotherapists; b) doctors, nurses, and all allied health; and c) healthcare systems as well as 7. Counselling and psychotherapy: a) helpful experiences; and b) unhelpful experiences. The framework was revised after the three cycles of PAR and feedback from key stakeholders, inclusive of co-researchers, members of the CF interdisciplinary team, and the patient population at our Adult CF clinic at The Ottawa Hospital. Again, the framework can be found in Appendix H and will be referenced herein. It is this researcher's hope that the experience of those with CF(RD), the impact of living with a non-visible illness/disability, CF(RD) positive aspects and meaning and purpose in life as well as how all of this lends itself to The Patient-Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis will be given depth and breadth in the following pages.

8.1 Section One: Focus Group Vertical Analysis

8.1.1 Focus Group One

General Characteristics of Co-Researchers. Focus group one took place on September 29, 2020, at 6:30pm, approximately six months after the COVID 19 pandemic began. This is significant for two reasons. First, the focus group and preparatory meetings were held on the virtual platform MS Teams to avoid cross contamination and infection. Second, COVID by now had considerably impacted the lives of all co-researchers, including in the areas of work, school, family, and social life. This will be further elaborated upon in the super-ordinate theme 1.g

Experience living with CF (RD) day-to-day- CF and the impact of COVID in the detailed analysis of the super-ordinate themes, subsets, and key emergent themes which follows.

All co-researchers in focus group one have a confirmed diagnoses of CFRD or have been flagged by the CFRD clinic interdisciplinary team as being at risk for CFRD and are therefore being followed for blood sugar levels and other markers that would put them at risk for the disease. A unique feature of persons with CFRD is that they typically have a higher treatment load than others with CF in that they are faced with at least two illnesses, CF and CFRD. This is evident in the super-ordinate theme 1.a Experience living with CF(RD) day-to-day- symptoms and treatments. Notably, all co-researchers in focus group one also fall within the age range of those in focus group three, those with CF aged 18-29, and therefore may have similar life stressors and developmental hurdles. This researcher will discuss this further in Section Two: Focus Group Horizontal Analysis.

Focus group one is made up of six co-researchers (Amelie, Sage, Veronica, Alice, Karina, and Jasmine), one English to Arabic interpreter, Diane, and our research assistant, Rebecca. For the purposes of confidentiality all names, except for that of our research assistant and this researcher, are pseudonyms and have been agreed upon by co-researchers. As previously mentioned, all attended via MS Teams inclusive of the interpreter for Sage, however, the latter opted to attend by telephone and could still be heard on the virtual platform. Alice and Jasmine co-facilitated focus group one with Rebecca (research assistant) as backup should either one choose to opt out for any reason and to act as time keeper.

To lend a richness to our understanding of co-researchers in focus group one, prior to delving into more socio-demographic details, this researcher will briefly introduce each co-researcher as they described themselves in the icebreaker exercise, “share something about

yourself with the group." Amelie loves animals and has two dogs, one cat and one horse. She has worked at a pet clinic as a dog trainer and aspires to have her own dog training business one day. Sage also loves animals and has a six-year-old Mexican Chihuahua that she recently sold because she had been hospitalized too much to take care of her. She got her dog because she felt lonely, lives alone and "has no family or friends or anybody." Veronica describes herself as a "homebody" who loves gardening, crafts and baking and is completing a business diploma during the pandemic. Alice "is a creative person" and plays the guitar, loves cooking, baking, sewing, crafting, woodworking and "all things do it yourself." Karina "is another homebody" and loves cooking, baking, and doing crafts. She is usually "way ahead" in her Christmas craft preparations. Jasmine loves music and singing and is yet another self-described "homebody" which all acknowledge is a commonality in the group.

Socio-Demographic Details. Please see Table 1 below for a visual representation of focus group one socio-demographic details, followed by a written summary:

Table 1

Focus Group One Socio-Demographic Details

Name:	**Amelie**	**Sage**	**Veronica**	**Alice**	**Karina**	**Jasmine**
Age:	19	23	23	25	28	29
Gender Identity:	Female	Lady Boy	Female	Female	Female	Female
Age at CF diagnosis:	2 days	11	1 day	2 months	2	First week of life
Language:	English/ French	English/French/ Arabic/Hebrew	English	English	English/ French	English
Living status:	Living with partner	Living independently	Living with parents	Living with partner/and roommate	Living with Spouse	Living with partner
Relationship status:	Partnered	Partnered	Single	Partnered	Married	Partnered

Employment status:	Full-time/ ODSP	ODSP	Student	Unemployed	Unemployed	Part-time/ODSP
Education:	Other	High school-Adult English and Math	University: undergraduate	College Diploma/ University: undergraduate	College Diploma	University: graduate
Are you a person with (CF18-30; CFRD; CF39 +; Other):	CF 18-30; CFRD; Adrenal insufficiency, DIOS, ABPA, Liver disease	CF18-30; CFRD	CF18-30	CF18-30; CFRD	CF18-30; CFRD	CF18-30; CFRD ?
Do you identify as a person with Non-visible illness/disability ?	Yes	Yes	Yes	Yes	Yes/No	Yes
Previous Counselling and Psychotherapy experience?	No	Yes	Yes	Yes	Yes	Yes

Ages of co-researchers at the time of focus group one ranged from 19-29. In terms of the gender identity of co-researchers five identified as female, and one as "lady boy." Age of CF diagnosis fell in the early diagnosis range for five out of six co-researchers, from one day to two months old, with one late diagnosis -Sage - at 11 years of age. Co-researchers cited English or English and French as their primary language (s) with Sage identifying "English some French, Arabic and Hebrew." Co-researchers resided in and around the greater Ottawa area. Living statuses included one co-researcher living with their partner and roommate, three living with their spouse or partner, one living with parents and one living independently. Five co-researchers identified their relationship status as partnered or married with one identifying as single. Two co-researchers cited their employment status as unemployed, two as Ontario Disability Support Program (ODSP) or another provincial equivalent and full- or part-time employment, one as ODSP, and one as student.

Four co-researchers had completed college and/or university inclusive of one with a graduate degree, whilst two marked "high school - adult English and Math" and "other" - as their education. In terms of identifying with one of the three groups in this study – CF aged 18-29, CFRD, CF aged 39 + - three co-researchers marked both CF 18-29 and CFRD, one marked both CF 18-29 and CFRD plus "adrenal insufficiency, DIOS, ABPA, Liver disease," one indicated CF 18-29 and a question mark beside CFRD, and the last marked in only CF 18-29. The latter two responses would be indicative of being investigated for CFRD rather than having a confirmed diagnosis. Significantly, all six co-researchers marked yes to identifying as someone with a non-visible illness/disability, however, Karina responded yes/no due to the circumstances of the pandemic, as follows:

> Alice: "CF and CFRD are both invisible illnesses – no visual indicator of either."
>
> Jasmine: "Other than physical symptoms of fatigue (dark under eyes) I physically can be identified as someone who does not have a disability due to my ability to hide my illness."
>
> Karina: "For the most part my illness feels invisible. During the pandemic however, it doesn't feel as invisible because of my chronic cough. I get looks and comments."
>
> Veronica: Yes, because I am not able to do the same things as a "normal" individual. Ex: I get sick more often which limits what I can do. Another would be that it would be unwise to become a baker due to the amount of flour that gets inhaled.

Finally, five out of the six co-researchers in focus group one marked yes to having had previous experience as a client/patient in counselling and psychotherapy, with one marking no but then indicating that they had been "forced into counselling" at one time participating in two sessions. The following are their response elaborations:

Alice: “I have seen the CF social worker for the last four years, but more consistently in the last one and a half years. Additionally, I was seeing a private therapist … for five months in 2019.”

Amelie: “As a teenager, I was forced into counselling during a lung exacerbation. After two sessions, they deemed my mental health stable.”

Jasmine: “I have been in therapy on and off since age 10.”

Karina: I have gotten psychotherapy in the past to help me during difficult times and to help me accept my illness. However, in the last years I haven’t had enough money to see a psychologist when I think I would have benefited.

Veronica: “I have been receiving counselling for approximately three years.”

PHQ-9 Scores. Fully four out of the six co-researchers in focus group one scored moderate (10-14) to moderate-severe (15-19) on the PHQ-9 citing their problems as anywhere from “somewhat difficult” to “very difficult” in terms of “how difficult problems made it to do work, take care of things at home, or get along with other people.” Two co- researchers scored in the mild range (four-nine) on the PHQ-9, citing their problems as anywhere from “not difficult” to “somewhat difficult” in the same life domains. The moderate to moderate-severe scores on the PHQ-9 of four co-researchers in focus group one alerted this researcher to their possible vulnerability and a discussion was had with each concerning whether they had ongoing counselling support. We also reiterated the availability of counselling support during and after the focus group as required. Two co-researchers who had scored moderate to moderate-severe on the PHQ-9 answered one (several days) to question nine on the PHQ-9, “Thoughts that you would be better off dead or hurting yourself in some way.” This researcher conducted a suicide risk assessment with both co-researchers utilizing the Columbia Suicide Severity Rating Scale (C-SSRS)

Outpatient/Ambulatory with a review of the C-SSRS Risk Assessment and Suicide Intervention Check List (Posner et al., 2011). One co-researcher stated that they "occasionally think about death in the way that if I got sick and died, I'd be okay with that" and "in general, I am more at peace with death, more so than the average person because of CF." They had no intent, means or plan and concluded, "I would not do it because of how it would affect those around me." The other co-researcher expressed her thoughts on suicide in the following way, "I only thought about suicide because I had a recent breakup and was angry." They had the means (sleeping pills from their GP) but no intent or plan. They stated that they would never follow through with suicide because "that would be devastating for those I love." Both co-researchers were being seen ongoing in counselling/psychotherapy, with the PHQ-9 repeated and relevant issues addressed, including exploring more adaptive coping strategies. Both continued to be monitored by their family doctors and one opted to increase her dose of antidepressant medication. Both felt strongly about continuing in the study, with one determined "to get the message out."

GAD-7 Scores. As two co-researchers were tied for the lowest GAD-7 score, their PHQ-9 and GAD-7 scores were tallied and the co-researcher with the lowest overall score was chosen to be interviewed. GAD-7 scores were the inverse to PHQ-9 scores for focus group one in that four out of the six co-researchers scored none-minimal (zero-four) or mild (five-nine) with three citing their problems as "not difficult" to "somewhat difficult" in terms of "how difficult problems made it to do work, take care of things at home, or get along with other people." Only one co-researcher falling in the mild GAD-7 range cited their symptoms as "very difficult." Two co- researchers scored higher, one in the moderate (10-14) range and another in the low severe range (15 +), citing their problems as "somewhat difficult" in the same life domains. Both co-researchers falling in the

moderate to severe range were being seen ongoing in counselling/psychotherapy and continued to be monitored by their family doctors.

Group Dynamics. There were two notable group dynamics in focus group one: 1) a robust sense of community developed amongst co-researchers, which this researcher will elaborate upon in super-ordinate theme 8.b. Feedback and suggestions re: PAR methodology -fostering a sense of community; and 2) whilst co-researchers mostly moved through the group developmental stages well, they many times got stuck at storming (the group encounters difficulties). This was due to "the alarming responses of one group member that caused concern and derailed things" and "others feeling torn between empathy and trying to stay on purpose and consider the needs of the whole group." In the end, focus group one did successfully complete their task and even the one group member, Sage, seemed to bond with the others. For example, she agreed that distributing the framework to the larger CF patient population would be beneficial to all, and asserted via her interpreter, "she's honoured to know all of you" in her closing statements. To illustrate the difficulty focus group one encountered, three exchanges with Sage (via her interpreter Diane) are outlined here, followed by brief comments regarding the exchange and then a summary statement. Anything in quotation marks here and in the comments or summary statement have been relayed to this researcher by co-researchers who prefer to remain anonymous in this instance regarding their feedback. The same procedure is used throughout the thesis:

Example One.

Diane (Sage): I love animals, specifically dogs. I have a Chihuahua Mexican Chihuahua that six years old. I sold it yesterday. And I feel so sad since yesterday and I want to go to the hospital, and I don't feel good because I'm so sad for it. I'm starting to feel shortness of breath. Oh I have sore throat now because I've been screaming and crying since I sold

it. Actually, I know I know. I had to sell it because with my condition I need to go to the hospital and there's nobody to take care of my dog. And two weeks ago. I stayed in the hospital for 25 days.

Jasmine: Wow

Diane (Sage): I had inflammation in two kinds of inflammation in my lungs. I had to stay at the hospital for a longer period of time, but I had. I decided to leave because of my dog his. He's alone at home. And nothing has helped. Nobody can feed him or give him food or take him outside. And I asked for discharge for an early discharge from the doctor because I was worried about my dog because maybe it died because it stayed like 25 days without anything. I consider my dog as my son. I love it. I take care of it. I'm not healthy and I I sold it to somebody with a better health will take care of him and doesn't leave him alone.

Jasmine: Wow.

Diane (Sage): And now I'm alone at home.

Jasmine: Wow, that sounds so challenging.

Rebecca: I'm sorry to hear about your dog.

Diane (Sage): Yeah, I got it because I was feeling lonely. I'm living alone and I have no family or friends or anybody.

Alice: We're all sending you big hugs.

Diane (Sage): Thank you so much, all of you.

Jasmine: Yes, thank you so much for sharing that.

Rebecca: Thank you for sharing.

Diane (Sage): No problem.

This exchange with Sage occurred at the outset of focus group one during the icebreaker exercise. The intention of the exercise had been to familiarize group members with one another; however, Sage begins with a "light" statement in sync with the others, "I love animals, specifically dogs," and then continues with a more dire statement, "I'm starting to feel shortness of breath. Oh, I have sore throat now because I've been screaming and crying since I sold it." Sage continues in this vein when she states that she left the hospital for fear that her "son" had died after leaving him alone for 25 days, and again when she talks about her purpose for getting a dog. Alice and Jasmine, both co-facilitators, as well as their backup, our research assistant Rebecca, respond with neutral phrases and empathy in the moment, however, all contacted this researcher (as did other co-researchers) after group to express their concerns for Sage and request follow up. It is worth noting that in her follow up telephone interview with this researcher Sage stated that her "boyfriend had helped to take care of [her] dog while [she] was hospitalized."

Example Two.

Diane (Sage): Oh, so do I talk about my health condition and the problems I face daily?

Jasmine: Yeah, so what it's like to live day to day with CF?

Diane (Sage): I have cystic fibrosis. And I have an implant in my two lungs. And I have diabetes type 1 and I have a problem in my pancreas. So, I take enzymes. I don't take good care of my health. I don't exercise. I just take my medication for the lungs. And my inhaler. And my spray. And some medication for my pancreas so that I would be able to digest the food I eat. I feel shortness of breath because I have to move the muscles of my lungs and I don't do that. I drink on a lot of sugary stuff and I don't take my insulin. Even after taking things with sugar. I don't advise anybody to do the same like me. I don't eat. I only take one meal per day. And sometimes I don't eat the whole day. Oh that's it.

Jasmine: OK. So, it sounds like it's been very challenging for her.

Alice: Thank you so much Sage.

Diane (Sage): I stop, I stop taking care of myself. I I stopped caring as a whole.

Jasmine: Thank you for sharing something so hard to talk about.

Alice: I think we all hear and understand you completely there, yeah. Sending more big hugs.

Jasmine and Alice: (laugh together).

This exchange occurs further into focus group one in response to Topic Guide question one, "Can you speak about what it's like to live with CF (RD) day to day– a few aspects of your experience that you would like to share." It is notable that Sage paints a somewhat grim picture of her treatment regime, particularly, the last few statements, "I drink on a lot of sugary stuff and I don't take my insulin. Even after taking things with sugar. I don't advise anybody to do the same like me. I don't eat. I only take one meal per day. And sometimes I don't eat the whole day." With everyone in group diagnosed with or being monitored for CFRD, they would be aware that Sage is "playing with fire," as one co-researcher stated. Again, co-facilitators Alice and Jasmine respond with neutral phrases and empathy. Sage is clearly driving home her point here, that she doesn't take care of herself. It is unclear if she is dissatisfied with their responses and returns with a more dramatic depiction to elicit more sympathy or whether her last statement is "just meant to shock." Regardless of her motives, co-researchers are becoming increasingly concerned. Finally, Alice and Jasmine "take the high road and attempt to join with Sage" showing that they identify with her inclination to "let go sometimes" regarding treatments.

Example Three.

Diane (Sage): So, my question is where is the cystic fibrosis located in the body? Because I changed my lungs, but where is it?

Karina: It's everywhere. It's in every single one of your cells. It's on the cellular level. It's in your protein. I forget the names exactly, but there's this protein that makes it that we don't get sodium chloride or sodium in ourselves. She still has it all through her body.

Alice: I think if Sage has specific medical kind of related questions, she should definitely reach out to her care team. We're here to talk about counselling and if she has those in-depth questions, she should definitely reach out to the medical professionals.

Diane (Sage): Before I finish my questions. I believe that there is no Coronavirus, and I don't believe it exists and I go outside without putting my mask on.

Rebecca: Oh OK, I just wanted to. So, I hear that. I just wanted to take a minute because we are at half time right now.

Sage has had a double lung transplant and she is unclear if she still has CF. She is a recent immigrant to Canada, having first been a refugee narrowly escaping familial abuse due to her gender identity, “lady boy.” It is likely that Sage has either not received adequate psychoeducation regarding her illness or that she has and there has nonetheless been a language barrier. Karina responds to Sage’s inquiry about CF with factual information, and Alice respectfully redirects to the research topic, counselling, offering some guidance regarding reaching out to the care team for “specific medical kind of related questions.” The co-facilitators had prepared for this potentially difficult situation, “what do I do if the group begins to talk about topics that are not relevant to the research?” in their training session. After the redirect from Alice, Sage comments on her beliefs regarding the pandemic. Everyone in the focus group is upset about COVID at this point in the pandemic and CF makes them more vulnerable to severe illness should they contract the virus.

This statement by Sage came across as "reckless and scary" to some. There is now a pattern in Sage's closing statements, overtly trying to press a point or shock. Her motives are unclear. Is she upset with the redirect from Alice? Rebecca acknowledges Sage's comment and then acts as timekeeper. There is no further attempt at empathy.

Summary Statement. The above exchanges with Sage have common elements and are repeated a few more times during group: Sage seems preoccupied with her own needs and experience; she fails to express empathy or resonate with the group; she exaggerates or misrepresents facts about her circumstances; end statements are a more shocking version of previous ones; and end statements follow neutral phrases and empathetic responses or redirects. Co-researchers attempt to empathize with her feelings and remain on task. The culmination of focus group one was positive, with invaluable feedback for the framework and "terrific bonding," however, the process could have been derailed. Many expressed gratitude for the co-facilitator training sessions. This researcher did follow up with Sage to assess her needs and ensure that she had a support system in place in the community. She expressed that being in the focus group had been a positive experience for her. Sage's exchanges in group were problematic for other group members, however, she seemed unaware of others' concerns in the follow up interview/debrief. There are many possible explanations for her behavior including a language barrier, past trauma, cultural differences in communication style and negative social determinants of health including education, poverty, and social isolation.

Transactional analysis is a theory, put forth by Eric Berne (1964/2016) that sheds light on group dynamics. According to transactional analysis, individuals operate primarily from one of three ego states, Parent (guiding/nurturing or controlling), Adult (reasonable, factual), and Child (emotional/ rebellious or compliant) (Berne, 1964/2016). Interactions between individuals

operating from different ego states may be contradictory or complimentary, depending upon whether both parties are happy with the transaction (Berne, 1964/2016). In the various exchanges with Sage, she seems to be operating from a Child ego state with others responding to her from an Adult ego state, as they try to remain on task. It is possible that Sage had expected a support group rather than a focus group and would have preferred to transact with someone's nurturing Parent. When this didn't happen, she further pressed her point with "shocking" statements meant to generate more empathy. She may also have felt resentment in these moments. Taken this way, the series of problematical exchanges in focus group one may be an example of contradictory transactions, unsatisfactory to both parties, and the storming stage of group development that everyone fortunately were able to move beyond.

Super-ordinate Themes. The following is an analysis of the eight super-ordinate themes and subsets (below) for focus group one. Relevant quotes will be highlighted along with the corresponding emergent themes to capture the profundity of the experience of co-researchers. A summary reflection will follow:

- 1.Experience living with CF(RD) day-to-day: a) symptoms and treatments; b) interpersonal relationships; and g) CF and the impact of COVID;
- 2. Psychological Impact of CF(RD): a) interrelationship of physical and mental health; and b) isolation from others with CF;
- 3. CF(RD) as a non-visible illness/disability: a) walking a line between sick and not sick;
- 4. CF(RD) and sense of self/identity;
- 5. CF(RD) positive aspects and meaning and purpose in life;
- 6. Observations and recommendations: a) CF(RD) counsellors/ psychotherapists-attitudes, knowledge and skills; and b) CF(RD) doctors, nurses and all allied health;

- 7. Counselling and psychotherapy experiences: a) helpful experiences; and b) unhelpful experiences;
- 8. Feedback and suggestions re: PAR methodology: a) general comments and dissemination of results; and b) fostering a sense of community.

Experience Living with CF(RD) Day-to-Day. Focus group one co-researchers centred their discussions on living with CF(RD) day to day on three themes or subsets: a) symptoms and treatments; b) interpersonal relationships; and g) CF(RD) and the impact of COVID, which this researcher shall elaborate upon here:

1.a Experience Living with CF(RD) Day-to-Day - Symptoms and Treatments. In addition to coughing, which is typical of CF, many co-researchers expressed experiencing symptoms of "fatigue" and "exhaustion," so much so that it caused them to become "homebodies," quit jobs to go back to school, and remain home due to the difficulty of working and maintaining one's "health at the same time." This may be attributable to having not only CF but CFRD as well as other illnesses (1, 2, 3). A reality of life with CF(RD) can include exacerbations as well as protracted hospitalizations for infections (4). The hardest part of CF(RD), according to Karina and Jasmine, is that it can "throw you a curveball" so that you think that you have a handle on the illness but then you realize that you do not which is not easy (5):

> Karina: Can I add something? I just want to say that I understand the feeling that you you've been born with this and you should know how to deal with it. But the thing about CF is it always throws you a curveball.
>
> (All nod in agreement).
>
> Jasmine: Oh yah (nodding in agreement). You think you've got a handle on it something else happens that well, it throws you for a loop and then you're like. You're starting to feel

> good and then you get a lung infection and then it's back to zero, always having to come back. It’'s not easy.

The treatment regime for CF(RD) is particularly arduous and up to two hours a day as it involves not only lung clearance therapies such as Hypertonic Saline and vigorous exercise, common for CF, but also blood sugar monitoring and insulin injections (6). Both Alice and Karina speak to this experience:

> Alice: Some aspects of my life day to day with CF include I have CF related diabetes as well, so it includes blood sugar checking. I have a freestyle sensor on the back of my arm. Insulin injections lung therapy. I have a nebulizer and I do Saline solution.
>
> Karina: I do have CF related diabetes as well, so I blood sugar checks and insulin. I did try that thing, but it seems to not work every time for me. So, and it's expensive as well. Even with insurance. So, I also do nebulizers as well, Hypertonic Saline, then the PEP, and then Colistin. The antibiotics after so I have about an hour of treatment in the morning and before bed. I usually try to fit in jog walk because my lung function is like 35% which is not very high. But very stable and good, so that's pretty much. I don't work because it's just too hard for me to maintain my health at the same time. That's pretty much my day. CF wise.

Some co-researchers such as Amelie have multiple diagnosis in addition to CF(RD) which can mean protracted periods on medications and erratic sometimes debilitating symptoms (7):

> Amelie: OK yeah, so I also have diabetes. I have liver disease as well. We're testing for adrenal insufficiency. I have the IOS which is chronic bowel obstructions which so far, I've been OK on. It's been probably about two years. I haven't had one and I also have ADPA which is kind of an allergy to Aspergillus, which is very very very severe for me. Anyway,

> so I've been kind of treated with Prednisone for that it's the first time that I'm off it … I've been off of it since I think January, so that's huge. Plus, I've been trying to get off it for like 15 years so that's a great thing. I think that's all my diagnosis for now, so I do about two hours of treatment a day and with my nebulizers and my therapies. I do the Colistin the Hypertonic Saline I do a lot of PEP or percussion if I have someone to help me with it … I also have the meter which I found worked really well. I was having kind of a hard time keeping up with the fingerprint, so for me that works pretty good. Otherwise, with eating, I find is another struggle, which I guess a lot of people are jealous of, but I have a hard time eating. There's sometimes I'm super great and I'll be eating five meals a day and I'm gaining a lot of weight and then other times I could have like half of a slice of pizza and be full going to puke. Plus, you're coughing. So, then your stomach kind of just tenses up, so that's another struggle that I have … Yeah, and (coughing. Laughs). All day every day.

Finally, some co-researchers with CF(RD), "stop taking care of themselves as a whole" either temporarily or permanently, in part due to the onerousness of the treatment regime or "treatment burden" (8, 9). Even with the "life changing" CFTR modulator Symdeco, a precursor to Trikafta, Amelie, for example, expressed that "treatment burden" can be persistent with "multiple layers" and "certain highs and lows throughout the year" (10, 11).

1.b Experience Living with CF(RD) Day-to-Day -Interpersonal Relationships. In describing their interpersonal relationships co-researchers in focus group one variously spoke about the impact of CF(RD) on family, for example, Veronica's mother who helped her with "percussion therapy" or Alice who described "coughing all over the place" and keeping her "partner up at night" (12, 13). Perhaps more profoundly many spoke about the loneliness that

comes with CF (RD), either due to losing friends to the illness, because they could not be consistently present or because they had experienced rejection from others due to the illness (14):

> Amelie: Of course, I've been losing cause we're talking about, you know, it being a lonely disease, and for sure, I mean, I've lost friends throughout. Basically, my whole you know through grade school and high school, just not being present cause it's hard to make friends when you're not there and you're in the hospital or at home trying to recover with fatigue and all that. So, for sure. One of my best friends is actually in Montreal, so it's been quite a journey. We don't see each other too often, but it's kind of uhh. So, we kind of roll with the punches … and it's hard for me to stay healthy, which is why I was losing a lot of friends and feeling lonely.
>
> Jasmine: Yeah. I definitely hear you. I hear a lot of things in that. I think a lot of us can relate to. Especially with losing friends or just disconnecting from them and then Um, always having to worry about all the sickness that we can catch.
>
> Diane (Sage): And being a sick person I'm sure there is no boyfriend who would accept me and with someone who would live her life part of it in the hospital. I tried to have several boyfriends, but the problem is that as soon as they know that I have these medical problems and that I go to the hospital a lot, they don't like to live with me.

Some, such as Amelie, attributed "a childhood of loneliness" and not developing "meaningful connections" to her frequent hospitalizations (15). On the other hand, she credited "great nurses" for helping her to feel a little less lonely when in hospital when her parents could not stay overnight (16). Others spoke about CF(RD) deepening their bond with family and friends because of sharing their struggles, and maintaining a smaller circle of trusted people who truly understand (17, 18):

Karina: And as for the positive, meaningful connections, I feel like when you share all your struggles with somebody like a best friend or whatever, you just have more you feel closer, like I don't know if it's like this with your families, but me my family were always really close because every time I got sick it was like OK let's rally together and help her through this and so, I just feel like the bonds I do have are really strong.

Jasmine: …and the fact for friends I have one best friend and that's it. And she's the person who understands like her and my husband. They're like my people and they understand, and I barely see her because every time she gets so much as a sniffle, she's like, no, I'm not coming over. I don't want you to get sick. That's what I love about her. She gets it. Sometimes it's about having a smaller circle to have people you really trust and that understand and sometimes that means explaining stuff to them too cause well, they don't know what it's like to be us.

Amelie: I'd say I'm in the same boat. Yeah, yeah I have my significant other and then one best friend and they're the closest people to me.

1.g Experience Living with CF(RD) Day-to-Day -CF and the Impact of COVID. COVID seems to have presented a "mixed bag" of experiences for co-researchers in focus group one, both negative and positive. In terms of negative experiences, with many now at home due to the threat of contracting the virus, finding employment with benefits to cover much needed medical supplies became difficult and stressful for Alice:

Alice: Um, for me I would be, yeah due to COVID trying to find a remote job that's really difficult. I was in school and working part time in March and I graduated in April and in March I moved back home as well a few hours away from all of my friends and my life and everything. And was there for four months but recently came back to live back in the

> city of Ottawa with my partner so that was like a big problem. Finding a job is a problem. I'm 25 now so I'm not covered by OHIP for any medical supplies, so insulin needles the Freestyle Sensors, so finding a job with benefits is also a pressing matter that is stressful and just adds another layer of things (19).

Others found COVID made their anxiety regarding interacting with others worse or they became fearful that their coughing meant that they had contracted the virus (20, 21). COVID meant further isolation which caused one co-researcher to "lose a group of girlfriends" who didn't understand her degree of caution (22). Yet another, Karina, was turned away from a fertility clinic because of COVID and her risk of severe infection. She and her husband had been waiting for this appointment for over a year (23). Finally, three co-researchers shared that people misinterpreted their coughing for symptoms of COVID, which brought to the forefront the invisible nature of their illness and resulted in them feeling ostracized (24):

> Karina: I'll keep it short, but mostly I know that my illness is invisible, but I think through this pandemic I've felt it the most because when I'm out and about I'm always coughing and that one of the COVID symptoms and the looks and sometimes comments you get. Oh, you should have stayed home. I went to do the grocery once when it was just starting, and this man was really rude to me. Yeah, I think mostly for me that's what I struggle with, especially during the pandemic.
>
> Jasmine: Yes, absolutely. 100% is those comments from people thinking we're sick when they don't know the context.
>
> Diane (Sage): It is. It is a handicap for sure because I can't walk at all. Like if I walk I feel totally short of breath so it stops me from doing things like that. And now it's becoming more and more difficult for me. Like the mask is suffocating me. I can't breath at all more

and more … with the mask. And when I start coughing, people run away from me. They think that I have Corona.

In terms of positive experiences related to COVID, one co-researcher expressed "not being super bored" now that she was home from a full-time job. Having her dogs and family around her and the time to focus on time-consuming treatments was perceived as "not a bad thing" (25). Another left her employment and took the opportunity to go back to school when she could no longer work at a forward-facing job, citing fatigue as an issue "either way" (26). Interestingly, three co-researchers expressed happiness because they were less exposed to germs and therefore healthier than they had ever been (27):

Veronica: Yeah. Oh yeah. Also, before COVID I got really sick all the time and this is probably the healthiest I've been because I haven't been interacting with people.

Jasmine: Somebody said this that during this COVID their health has been kind of better. And more stable because there's less interaction with other people, and I find that that's been pretty true for me too…

Amelie: And of course, with COVID it's been one of the healthiest times of my life. I mean, I've finished high school about two years ago and it's been the healthiest I've been cause my job is pretty private. I mean I work at a little clinic. So sometimes like yes, I deal with the public, but it's a lot less than being in a school full of people. So, I've been healthier cause I mean, it's kids and teenagers. You'll have a bunch of disease going around and you touch doors and thousands of other people have touched and it's hard for me to stay healthy.

2. Psychological Impact of CF(RD). The super-ordinate theme psychological impact of CF(RD) for focus group one is divided into two subsets: a) interrelationship of physical and mental health; and b) isolation from others with CF (RD), elaborated upon here:

2.a Psychological Impact of CF (RD)-Interrelationship of Physical and Mental Health.

Co-researchers in focus group one felt very strongly that their physical health and mental health were integrally connected, observing that if they overlooked their mental health this would result in their physical health declining sometimes to the point of developing lung infections or being hospitalized:

> Amelie: If you're coming back to mental health and physical health all come back to one piece if that when mental health piece is overlooked then your physical health is gonna go down there … Yeah, I mean it's always been whenever I got to low point in my emotions I always get really sick and have to go to the hospital, so either I get sick physically and then my mental health would deteriorate and then I go in the hospital or mental health then physical, then go to the hospital. So, either way it's damned kind of either way (28, 29).

The connection between mental health and physical health is further expounded upon by Jasmine who describes a cycle, or a "double-edged sword," whereby her physical health negatively impacts her mental health, which adversely impacts her physical health. This is evident when her anxiety and depression get in the way of getting out of bed to do treatments:

> I think what's probably the most challenging other than the fatigue every day and feeling exhausted and probably the mental health and the depression and the anxiety that comes with it and feeling so down that it's so hard just to get out of bed to do your treatments. So, it's this double-edged sword where you need to get out of bed to nurture your body to stay alive and then at the same time your mind is just making your body feel that much more heavy on top of CF, so it's something that's really hard to battle sometimes (30).

Amelie draws a connection between CF, mental health, and shame, which Jasmine concurs with. According to Amelie and Jasmine, the expectation is that one should be able to cope with CF

having been born with it which might result in feeling "ashamed" if one's mental health suffers and delaying the counselling/psychotherapy one needs:

> Amelie: I find that mental health has been something I have not really addressed because it seems like it's less of a priority, but it takes a toll on your health if you don't address it and I think it's been something I've been kind of ashamed of. And why I haven't gone to therapy for that cause you know, people think, oh, you've had that your whole life, well you should be used to it by now. For me, that hasn't been the case. It's always kind of. We'll call it a burden, I guess, but it's been a part of my life (31).
>
> Jasmine: I thought that was really interesting when you said Um, that shame part that you feel for going to therapy cause CF is something we were born with or diagnosed young with and we live with it for so long, so it's kind of like we're supposed to be the experts on how to hold that on our shoulders, but it's really something that can at the end of the day, we're human and it can be crushing (32).

Finally, CF (RD) sometimes means having to face difficult emotional dilemmas, such as Karina's, the choice between having a biological child or starting on the potentially lifesaving medication Trikafta, which resulted in anger, stress, and grief. Karina makes a direct link here between stress and lung infections:

> Karina: But in March, the doctors with the CF clinic throw a bomb on me that says you qualify for the compassionate program for Trikafta. You know, one of the newer drugs, but there's a catch. You have to go back on the pill and you've gotta stop trying for a child. So, it was a whole thing. It took me months to figure out what I wanted because I kept going back and forth … So, it was a whole thing and I had to be like, well, do I want biological children, or do I want just children? So, I'm a little mad at the government right now. They

> have to make me choose between my health and a baby (crying) … Yeah, that's a whole grieving part process, but my husband helped me through it. Took classes so we could become foster parents, so we're starting that process. So that on top of hopefully soon I will be able to apply for this life saving drug and I gotta tell you better be worth it … I'm also a very anxious person. Just a little bit of stress doesn't help at all because too much stress causes lung infections too (33, 34, 35, 36).

2.b Psychological Impact of CF (RD)- Isolation from Others with CF. One of the most difficult psychological impacts of having CF is the fact that one cannot interact with others with the same illness because of the risk of cross-infection. The emotional impact includes feelings of loneliness which can be "devastating:"

> Jasmine: It can be a very lonely illness sometimes, especially since we can't come into contact with each other. I think that's one of the most unique and devastating things about our illnesses is that (37).

Jasmine also speaks of feelings of alienation from those around her who cannot relate to being in her body, which is "tough:"

> Something that keeps us so connected and that we experience so much we can't even touch one another and so just constantly relating to people who don't really know what it's like to be in this body can be really tough (38).

Finally, Amelie acknowledges an additional psychological implication of living with CF (RD) in isolation from others with the illness, which is no less impactful. Not only do persons with CF (RD) need to remain apart due to the risk of cross-infection but also to protect themselves from getting too close and experiencing loss, which is "scary."

> Amelie: I found it kind of scary, though, I didn't want to get too attached to other people with CF, so I had a hard time keeping up those connections, but for some people it worked great (39).

3.a CF (RD) as a Non-Visible Illness/Disability - Walking a Line Between Sick and Not Sick. This super-ordinate theme and subset can be summarized by the following statements by Alice and Jasmine, and beg the following existential identity questions, how does one walk "that line between sick and not sick?" When one's illness/disability is non-visible, and symptoms are fluctuating how does one represent oneself to the world? Under what circumstances do you decide to disclose your illness/disability or keep it concealed? (40):

> Alice: So, walking that line between like sick and not sick, disabled and not disabled like how you know when to pull the card and how do you know when to tough it out and yeah, be more normal. You know to fit into spaces. I think having an invisible illness makes that choice really difficult and like prevalent for me in my life and I hate that.
>
> Jasmine: Oh my God, yeah, so glad you brought that up. That's really interesting that you bring that up. I think that's like a huge thing that a lot of people with CF battle with too, especially if they are more physically active and physically capable and fit, depends where your body is at and where you are in your journey.

Alice further embellishes upon this point and adds in the element of identity, which will be further developed in the subsequent super-ordinate theme: CF(RD) and sense of self/identity. Having CF (RD) means not looking sick but feeling sick, sometimes feeling well relative to others on the spectrum of CF (RD) but not well enough to fit in as "normal:"

> Alice: Kind of along those lines, um, of having like. Of not looking sick, but feeling sick is, um, I'm fortunate enough to be really healthy and be really fit and play sports and have

> done that my whole life. And then sometimes when CF does become an issue when I am rundown when I do have to take antibiotics. When I had my hospital admission like you kind of feel like I'm not sick enough to be included with the rest of the CF population who are objectively sicker more often than I, but I'm not healthy enough to fit in with the normal people who don't have CF (41).

This struggle between "being in feeling normal and being in feeling sick" can occur in non-intimate relationships, for example, in the workplace, in interactions with acquaintances and with professors at school, where misunderstandings can arise and cause difficulties in receiving accommodations or in forming friendships:

> Alice: Yeah, it's hard to figure out what can't be fit in and people around you. Most people like acquaintances or like colleagues or like your boss don't always like understand that you're literally battling between like being in feeling normal and being in feeling sick (Many nod affirmatively) (42).
>
> Veronica: Also, probably with when I was in University. Some of the professors. If I'd be asking for an extension, they wouldn't quite understand why, because I looked fine even though it was for medical reasons … I'd say for me, especially when dealing with people I don't know very well, say get invited to an event. They can probably think that I'm just brushing them off if I have to cancel too often and I'm just sick or not feeling that well that particular day (43, 44).

Having a non-visible illness/disability, can be more difficult to process emotionally when partners, close family, and friends, fail to recognize that although looking "great" on the outside one does not feel well "on the inside." Emotional implications of feeling unseen by those with whom one

feels close can include feeling "rejected," difficulty "validating [one's] own experience" and "denial."

> Alice: Yeah, they're dismissive about it, and I don't think intentionally or maliciously but like even a comment like you look great what that's like such a backhanded thing cause you're like, what? What am I supposed to look like? Oh my God like that makes me feel worse. That makes me feel rejected even more (45).
>
> Jasmine: But it's definitely challenging when you feel so horrible on the inside when you're really, really sick and people are like, oh, you look great. So that can be really hard to compartmentalize and really absorb mentally when you're trying to validate your own experience. With your illness, when people don't see it, it's really hard to deal with that (46).
>
> Amelie: On that topic, I feel like a lot of us struggle also with denial, in that like I'm never the first one to say, oh yeah, I'm gonna go get checked out for any antibiotics (47).

Finally, there are advantages to having a non-visible illness/disability because, although challenging to hide symptoms when overt, when symptoms are less overt one can choose when to disclose therefore "avoiding getting judged right away." All in group one acknowledged that they have become "good actors" in part for this reason (48, 49, 50, 51).

4. CF (RD) and Sense of Self/Identity. As evidenced by the previous super-ordinate theme, persons with CF(RD) struggle with their sense of self/identity in part because their illness/disability is non-visible and therefore how they feel on the inside is not representative of how they look on the outside, obfuscating people's perceptions of them and their own concept of themselves (52, 53, 54). Furthering this notion, persons with CF(RD) can feel different than

persons who are “healthy” or “normies” or who “don’t know what it’s like to be us,” which can at once be isolating and consolidate a collective identity (55):

> Karina: But like it's just a different world. It's all our problems are not the same thing. Yeah, they're hard for people that are healthy to understand. That's all (56).
>
> Amelie: [My friend] didn't even get the lungs which is something I was really hoping for. Rooting for her. And I needed a little bit of help to get over that hump because as much as we weren't close (hands together), we were close through other ways that even some "normies" (air quotes) can't understand (57).
>
> Alice: Yeah, thanks for sharing that. I think that's something we can all relate to. I think it's funny that I think Karina you brought it up earlier where you're like Oh my God, we all sound the same we're all coughing….and I like that. That brings us together. But I also understand from the rest of the world that's a really isolating experience for everyone (58).

Finally, Jasmine describes her journey in integrating CF into her identity, learning from her experience and “growing stronger,” moving from a place of “rejecting it” to “fit in” to a place of “acceptance:”

> Jasmine: I think for the non-visible disability part I feel for me as a teenager, I think for the well I'm 29 now and as a teenager I fought so hard to hide this illness to fit in and to reject it and to you know, put myself in situations even when I was feeling so sick and so uncomfortable. And then eventually I find, at least for me personally, as I've grown up, you are slowly learning to accept this illness and what it's teaching you and your challenges and growing stronger from it. And then eventually I feel you're able to reach this space where you're kind of able to accept it. And deal with those comments from people and be assertive and stand up for yourself. But kind of realized what you can and can't control (59).

5. CF (RD) Positive Aspects and Meaning and Purpose in Life. Despite the inevitable hardships of living with a chronic illness/disability co-researchers in focus group one described various positive aspects to living with CF(RD), for example, “learning to stand up” for oneself, “meeting really nice people” and finding “meaningful connections” (60, 61, 62). Amelie describes maturing “a lot quicker” as a result of having to contend with a life limiting illness/disability that could mean extended periods of time away from friends and thus “finding out who your true friends were:”

> Otherwise, it made me mature a lot quicker. As a kid I mean you had to deal with stuff that not a lot of kids had to yet to stand up for yourself. You had to do all these little things that seem insignificant, but they make a big big big difference. Within all that and you could find out who your true friends were really quick cause when you weren't there, they'd text you or they'd come see you. Or not. It would teach me to not have expectations and like don't plan too far ahead and be disappointed. And if things don't go as planned, well, too bad. It's just how it is (63).

Positive experiences can also come from the knowledge that one’s health can be compromised at any time, therefore learning to have “perspective,” caring less about the “drama … in other people’s lives” and “appreciating the moment.” Her is an exchange between Veronica and Alice that speaks to these points:

> Veronica: So, I'd say for me, it’s definitely given me the perspective of sort of caring less about the little things or drama uh, that goes on in a lot of other people's lives.
>
> Alice: Uh huh. For sure you have to focus on big picture, and you have to focus on yourself and that's more important than any other petty stuff that can get in your way.
>
> Veronica: Yeah, and it's also definitely for me sort of enjoy the little things.

Alice: So yeah, being able to embrace those and appreciate the moment for what it is, cause it's important to do that. Yeah, good for you.

Veronica: For sure (64).

When discussing what gives them meaning and purpose in life, co-researchers in focus group one turned to the subject of work, specifically, experiencing capricious productivity, finding a career path that fits within one's lifetime and falling short of society's expectations but coming to accept a new focus in life:

Amelie: I find that that's kind of a hard question because some days are super great and other days, you're feeling kind of down in the dumps and you have no clue. So, some days I feel super productive other days it's like well, what am I doing? And I mean it's changed kind of the course of you know, like this was before Trikafta and Symdeco and all these different medications came out. But I figured I wasn't going to be anything that took a very long amount of school like a doctor or a vet or a lawyer or whatever. I didn't feel like I would have the time to do that after I graduated from high school. Um? So that kind of changed that career path so I was trying to structure or something and making sure that I actually have time to do that within my lifetime (65, 66).

Karina: For a while when I figured out I couldn't work because it would just not be sustainable with me and my health, [related to] purpose and stuff, I just felt like I wasn't contributing to my life with my husband and for a long while I felt very useless and like I couldn't contribute. So, I'm kind of a housewife I guess because I could clean as much as I can, but my husband helps me a lot, but that was something that because when you talk to people, what's one of the first questions they ask you? They ask you, what do you do? (Everyone nods) And my job is to for the longest time it was hard for me to just say, well,

my job is taking care of my health. I have CF…But I don't struggle with it anymore but at the beginning (67).

The responses of co-researchers in focus group one adds a scope and breadth to Frankl's three core principles: freedom of will, will to meaning, and meaning in life (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Frankl et al., 2010). In the face of suffering, many learned from their experiences, developed new skills, connections, and perspective. Being that CF (RD) is a spectrum with symptoms fluctuating daily and the severity of the illness/disability varying between individuals, some have found meaning in the labour force whilst others have found purpose in taking care of their home and their health. All chose to find what was uniquely meaningful to them.

6. Observations and Recommendations: a) CF(RD) Counsellors/ Psychotherapists- Attitudes, Knowledge and Skills; and b) CF(RD) Doctors, Nurses, and all Allied Health. Focus group one's sixth super-ordinate theme is divided into two subsets, with the latter indicative of PAR's iterative process, adding an unexpected dimension to this thesis and the patient-centred framework. All findings have been incorporated into the Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

6.a Observations and Recommendations for CF (RD) Counsellors/ Psychotherapists- Attitude, Knowledge, and Skills. Having shared with one another their most intimate experiences of living with CF(RD), the psychological impact of CF(RD), CF(RD) as a non-visible illness/disability, CF(RD) and sense of self/Identity, and CF(RD) positive aspects and meaning and purpose in life co -researchers in focus group one had a clear picture of what they would require of CF(RD) counsellors/psychotherapists to meet their needs. This super-ordinate theme

and subset are further divided into the following areas: attitude, knowledge, and skills, in part because co-researchers are responding to Topic Guide questions five and six – 5. What attitudes are important in your counsellor/therapist for you to feel like you can talk openly with them? 6. What knowledge and skills are important for your counsellor/therapist to have in order to work with you most effectively? – and "since these three areas encapsulate what [co-researchers'] look for," according to one, when seeking counselling/psychotherapeutic support. Importantly, co-researchers found these three areas so crucial that the patient – centred framework is likewise apportioned.

Attitude. Fully four co-researchers in focus group one cited not feeling judged as a prerequisite to being able to talk openly with a counsellor/psychotherapist. Similarly, being open-minded, friendly, appropriately self-disclosing, a good listener, showing empathy and validating co-researchers' experiences were cited as important attitudes to feel supported. Amelie speaks of possibly feeling judged as her reason for holding back from seeking help for all this time and non-judgement as a necessary condition to "letting it out." She seems concerned both about judgement from a counsellor/psychotherapist and too about her own skill in "letting it go." The latter may emanate from "a childhood of loneliness" and not developing "meaningful connections" growing up with several chronic illnesses, and perhaps from her own internalized critic after years of being judged by some in the medical system. The former will be elaborated upon here and in super-ordinate theme 6.b Observations and recommendations for CF (RD) doctors, nurses, and allied health:

> Amelie: I feel like for me anyway, and again kind of the reason why I haven't taken the steps yet to go is that I have a hard time with that, like letting it out like I think it's a skill

> as well. Just feel like you can let all that out on someone and not feel judged not feel all these things. You know that it's OK to just let it go (68).

Jasmine talks about her experience "from both sides" as a client and as a psychotherapist, and the prerequisite of nonjudgement to "opening up about your deepest, darkest feelings." She also sees a relationship between the qualities of open mindedness and non-judgement "which go really close together:"

> Jasmine: Yeah, good question. A lot of what I've heard everybody say is definitely elements that I try to incorporate when I'm in the therapy chair as the therapist. Not being judgemental is probably one of the most important ones. If you feel judged by your therapist, you're really not gonna wanna open up about your deepest, darkest feelings, so I think that's a big number one from both sides, cause I need to feel that from my therapist too … And then yeah, that open mindedness. I think my therapist really embodies that… for sure and that open mindedness and non-judgmental kind of go really close together, so I think those are some big qualities for me (69, 70).

Veronica also references open mindedness and the need for non-judgment from her counsellor/psychotherapist as a counterpoint to CF (RD) clinic appointments, where she has felt judged at times by doctors for "trouble getting to do [her] treatments" which can impact her mental health. Alice followed this with a comment about dreading "white coat scrutiny," a precursor to super-ordinate theme 6.b Observations and Recommendations for: CF(RD) Doctors, Nurses, and all Allied Health:

> Veronica: So, for me, definitely, as you mentioned, that open mindedness and supportive and then also, in comparison to more of a CF clinic. I guess non-judgmental of if you are having trouble getting to do your treatments that is then affecting your mental health. I

> definitely find it's more important and very helpful when the counsellor judges less than a doctor might.
>
> Alice: That's a very good point. I'm sure we kind of felt that white coat scrutiny and we're like Oh no, and we just dread it. That is such a good point (71).

Amelie has likewise been impacted by her encounters with doctors, the way that they "will look at [her]" if she neglects to do her treatments and shared her reluctance to open up due to the expectation that a social worker would judge her as well, despite her experiences to the contrary. She concludes that being sincere, open minded and having a friendly connection are vital "to talk about treatments or mental health or how you're feeling," especially in an ongoing therapeutic relationship:

> Amelie: But it's just the way a doctor will look at you when you would tell them you neglect to do your treatments or you're not exactly doing what you should be doing, and we all kind of go through that kind of phase. I feel like I would get judgment from a social worker coming from like treating a CF patient. But yet, the social worker that I had at the Children's Hospital, she made you feel and I don't know what it is. But when you just feel comfortable around someone and it's just some people have it some people don't and I don't know how to explain it, but I guess being sincere and being open and just making you feel welcome … cause it's just you feel more open with the person whether it's to talk about treatments or mental health or how you're feeling. It's important to I think have more of friendly connection and especially if it's a reoccurring, like if it's a person that you can go to talk to often not just once in a blue moon (72).

Finally, "good listening," validation of one's experience and therapist self-disclosure in order to have the relationship less "one sided" and contextualized are mentioned by co-researchers

as important attitudes and skills on the part of counsellors/psychotherapists to open up (73, 74). Alice summarizes "good listening" as follows:

> Good listening is important. I know like I can go on and on and on and speak 1000 words but like they didn't mean anything or I was just like blabbering on and I know like my therapist will kind of be like OK so what you're saying is this and this and this and I'm like oh (Veronica nods) you just translated that from my complicated Alice language, like I don't even understand, so that's really important. The good listening for me, validation is really important. So, when I am upset about something or feel guilty for having some type of feeling being validated that what I'm thinking is OK it is important (75).

Knowledge. Co-researchers in focus group one emphasized that knowledge of chronic illness is important for a counsellor/psychotherapist in working with those with CF(RD), especially its effect on "all the complexities that come with it like grief, depression, anxiety" (76, 77). As example, having good background knowledge of chronic illness on the part of one psychologist helped Karina to move past denial and finally accept her diagnosis of CF:

> Karina: I think a really good thing I want is good knowledge of chronic illness because honestly, sometimes they just don't get it. If they have no knowledge of CF, they think I don't know what they think, but it's just like it's not the right mindset they have in their head. They think you're a normal person and of course we're normal in some degree, but the things we struggle with are not. So, it's just a few years ago now almost 10 years ago I had a hard time accepting my illness and I was not compliant. And I went to a psychologist that specializes in chronic illness and she really helped me through. After a few months of really accepting what was happening to my body and how much it was changing and that helps a great deal. Like when they're specializing, chronic illness I really think there should

> be like some kind of formation or something for chronic illness. Not specifically CF, but if you wanna do it specifically for CF go ahead (78, 79).

Amelie thinks it important that counsellors/psychotherapists not only have basic knowledge of chronic illness but also the day-to-day struggles of those with CF(RD) because "it might not be quite so simple," CF is a degenerative illness with new diagnoses added throughout one's lifetime:

> Amelie: I think it's important to understand that if you're saying the patient's day-to-day life, what they have to go through different struggles, it'll go throughout their life…. And of course, like your health declines throughout your life, you get other diagnoses added, so there's a lot of different things that happen to us that they need to be able to help us go through and it's not just one mental illness or it might not be just quite so simple (80).

Skills. In terms of skills for counsellors/psychotherapists working with those with CF(RD) co-researchers in focus group one discussed a few "essentials," for example, the importance of empathy, helping to put their experience into words, utilizing an individualized approach and encouraging them to sit with their difficult emotions. One co-researcher introduced two unique ideas for skills based on her personal experience: helping parents to cope ("they are dealing with things too") and conferring a mental health diagnosis to "be honest" with oneself about mental health issues and move past denial (81, 82).

Jasmine speaks about empathy as "key," particularly starting where the client is at, which means not forcing or imposing positivity but being able to meet them even in "dark places." To do otherwise would be counterproductive to the psychotherapeutic process. Again, speaking as both a client and psychotherapist she employs a colourful expression from her own training as a psychotherapist to describe this:

> I think empathy is really key in being able to meet your client where they are, with what their feelings so not forcing positivity on them. Or I think in one of my training a funny term they used was a sunshine enema. Meaning you don't wanna blast them with a whole bunch of positivity when they're in a space where they can't receive that. It's inauthentic. It's really counterproductive to the whole process. So just meeting the person where they are, no matter how uncomfortable, no matter how dark it is (83).

Others in the group pointed to their difficulty putting their inner experience, their thoughts and emotions, into words and the importance of a counsellor/psychotherapist asking the right questions to enable them to understand themselves better and to feel like they are making progress:

> Amelie: To have also your therapist kind of put your emotions into words when you don't really understand what you're feeling or when you don't know how to explain something. I think that is something that's really important…So, kind of a clear image or clear path on what's going on … I think if you're really able to communicate to that person, put your feelings together, clear path … understand what's going on … to leave with a good feeling or in the direction of you know progress and not regressing (84, 85).
>
> Veronica: That the therapist asking questions is also super helpful and I find that as well because I am also a very closed person, so I find it hard to express myself and I don't sometimes know how to put things into words. So, asking questions can definitely help (86).
>
> Jasmine: Connecting, asking the right questions … you're like slowly climbing that mountain (87).

Amelie stresses the importance of a counsellor/psychotherapist having an individualized approach tailored to one's personality type or coping style, for example, "outgoing or closed," likely in

consideration of her own difficulties opening up. Alice reiterates this point, bringing in the idea that an individualized approach would help in terms of knowing how one likes to feel "nudged" and "supported:"

> Amelie: Of course, your patient will have some other issues but to also go with their personality type because everyone's different. Some people more outgoing, some people are more closed off, so I think it's just to go with what works better for them. What coping mechanism works for them and all that… Sort of an individualized approach (88).
>
> Alice: Yep, you're totally right. It definitely takes your therapist getting to like know you a little bit in order to know how you like to be nudged and what kind of support you need to receive. So, that's a great recommendation for therapists dealing with people with CF for sure (89).

Finally, Alice speaks to the importance of the counsellor/psychotherapist encouraging you to sit with your "hard emotions," so that you discover that they are not in fact "scary." Jasmine reiterates this point and the important skill on the part of the counsellor/psychotherapist of "slowing you down" and "creating that safe space" to support you to do so:

> Alice: Super helpful is every time I get worked up and emotional about something, it's likely because I'm super uncomfortable feeling my like hard emotions so a really helpful experience for me is like every time my therapist says stop, stop, stop, stop, stop, stop. How are you feeling? And I have to be like I'm sad and then she's like, OK then, let's just let's just stop and just sit with that for a second. So, I just have to like sit there and cry and then I'm like OK that wasn't scary as I thought. So, being able to help me learn how to sit with the hard stuff has been a really helpful experience for me.

> Jasmine: So, it's kind of like somebody who can slow you down and make you get in touch with your emotions, but kind of still creating that safe space where it feels like you're able to reach that place and you know you have somebody there supporting you with you in the moment. And then … it wasn't as scary as I thought it was going to be (90).

6.b Observations and Recommendations for CF (RD) Doctors, Nurses, and Allied Health. Super-ordinate theme 6.b represents a surprise finding for this thesis study as Topic Guide questions at this point had been geared toward "necessary counsellor/therapist attitudes, knowledge, skills and what would constitute A Patient-Centred Framework for Counselling and Psychotherapy with Persons with CF" and not toward any observations and recommendations for the CF interdisciplinary team. By this time, co-researchers had become comfortable sharing with one another, however, and had turned their thoughts to the larger question of how mental health had been addressed in CF clinic overall. Again, PAR is an iterative process, and exploring unforeseen but related topic areas is expected. One observation and recommendation is the idea that social work/counselling be more integrated into the CF team so that all patients are made aware of the service and that any members of the interdisciplinary team can make a referral when they have had a difficult CF clinic appointment and are in need of support:

> Alice: With patients, yeah, it's definitely important to I think even having your nurse bring it up in visits, I think. You know it's important not to keep pushing it on you, but to keep reminding you that the resource is there (91).

> Karina: So, the only thing I have to say that I find would be helpful is that I think this team and the social worker should talk more. I think that when we've had a hard visit because it happens, sometimes you're disappointed about your PFT [pulmonary function test], or like the thing with me and the whole Trikafta thing …like if we're open to that obviously, but I

> think that's something they should consider doing … especially when we have a tough one. It would be helpful to have somebody get back to us, especially with coping. Now you can just call us and ask us how we're doing. You don't have to go in (92).

Here, Amelie recommends that every doctor learn to treat each person differently when it comes to mental health, less as "a medical case" and "more as a person:"

> And I think that goes with every doctor as well. Like I, I just always feel like you know when you're dealing with mental health, you treat the person more as a person then as a medical case because you're there to talk more personally. But even those doctors, whatever respirologists you need to treat them as a person (93).

7. Counselling and Psychotherapy Experiences: a) Helpful Experiences and b) Unhelpful Experiences. This super-ordinate theme aligns with answers to Topic Guide question eight, "If you have reached out to a counsellor/therapist within or outside of the hospital system what experiences stand out for you that you would like to share: a) Please give examples of any helpful experiences; b) Please give examples of any unhelpful experiences." Co-researchers reported a disproportionate number of helpful to unhelpful experiences, 10 to two, however their answers to the latter were equally poignant. Super-ordinate theme seven also informs the patient-centred framework (Appendix H).

7.a Counselling and Psychotherapy Experiences - Helpful Experiences. Helpful experiences for co-researchers in focus group one aligned with their observations and recommendations for CF(RD) counsellors/ psychotherapists - attitude, knowledge, and skills. For example, co-researchers reported counselling/psychotherapy experiences as helpful when the therapist aided them to understand their thought process, to be honest with themselves so that they can understand their emotions, which to one had been happily "shocking," and helped them to sit

with their sometimes "dark scary feelings" (94, 95, 96, 97, 98). Co-researchers also found it helpful when the therapist expressed empathy and compassion and validated their experience so that they felt heard and seen. Finally, they valued being challenged and given relevant resources, feeling empowered that they had learned new skills and noted the benefits of establishing trust with one's therapist because that learned skill then spills into other important relationships.

To elaborate, Jasmine and Karina spoke about their helpful counselling/psychotherapy experiences as follows. In the first instance, Jasmine notes that being seen and heard, feeling compassion and empathy help her to "let it all out" and understand that she is "gonna be okay" (99). In the second instance, Karina and Jasmine have an exchange regarding feeling validated, how that helped at a very difficult decision-making juncture:

> Karina: I haven't had therapy in a really long time except a few months ago when I talked to the CF therapist and it was a good experience because I talked about the whole child by you and I was explaining to her my thought process and everything I had processed and she was like wow, you're so organized and you're making sure you have everything figured out and like, even if you're unsure you're making sure that every opportunity is open to you. And somehow, I didn't feel that way because I was keeping going back and forth and all confused and she was like you're doing everything right. Like you're preparing yourself and that was a great experience because I got validated in that way and I thought that was great. Really helpful.
>
> Jasmine: Yeah. Yeah, thank you for bringing that up. That being validated. I think that's an amazing feeling to have in therapy. When you feel heard and seen and understood (100).

Alice expressed feeling both validated and challenged as important in therapy as well as the counsellor/psychotherapist recommending relevant resources to further consolidate learning. Alice

also speaks about feeling empowered when you've realized that you have carried over the skills you have learned, followed by Jasmine:

> Alice: My best therapy sessions were validating. They were challenging. Probably cried. My therapist always recommends like exercises or books or gives me sheets on cognitive distortions or like anything like that. So, it's like at home like for me to work on is good. I'm a good student that way, that's why I like those kind of resources to be able to practice what I just tried to like learn (101).
>
> Alice: And then what I think what makes a session sparkling for me is I walk away feeling empowered because I'm no longer like scared of what I'm feeling, and I just own it or like completely bust it because it was busted up thinking in the 1st place … So … I kind of feel those like gears turn and know that I'm reacting differently now than I did six months ago towards a situation based on like those skills that I've learned. Also makes me feel like I've had progress and that makes a session kind of come full circle and be amazing for me.
>
> Jasmine: Yes, when you're finally realizing your life that you're carrying those skills with you that you've learned in therapy. Like that Oh my God, I'm doing it. Yeah, I totally resonate with what everybody said (101,102).

Finally, Jasmine introduces the idea of transferable skills, noting that finding trust with a therapist has helped her to find trust with other people in her life:

> I think a big thing about that, too, is just establishing that relationship with the therapist and that trust and once you're able to kind of do that with your therapist eventually being able to do that with people in your life. Once you kind of learn that trusting bond with somebody and feel empowered (103).

7.b Counselling and Psychotherapy Experiences - Unhelpful Experiences. Two unhelpful experiences in counselling/psychotherapy experienced by co-researchers in focus group one generated some intense feelings and discussion. The first unhelpful experience concerned a therapist that Alice had seen who had not been paraphrasing (and perhaps listening) well, thereby resulting in her feeling "misunderstood" and "putting up a wall." She described the overall experience as "disheartening" (104, 105). The second unhelpful experience had Karina, Amelie and even Sage (who had been mostly silent in this line of questioning) engaging in conversation, with Jasmine in agreement as co-facilitator. The main idea had been that social workers/counsellors/doctors should not be forcing their opinions onto those with CF(RD) or any patient as this undermines their experience-based knowledge and is counterproductive, with few following their advice. Again, there is a reference to doctors perhaps not "treating them as a person" but instead telling them what to do, a repeated refrain in this study:

> Karina: Yeah, [well the thing I find unhelpful] mostly it's when they're trying to push their opinions on you or what you should do. Like I can't work, it doesn't work for me. In the past, social workers have pushed me and said you should. I can send you links to jobs and le le le le, but that's not what I want. I want somebody to listen … I would want to have a job, but it doesn't work for me, so don't push it on me. A job or higher education because I know it like I've gone to college, but one pushed university on me and I know that wouldn't work for me. So, don't push your opinions on me or how I should take care of myself because I already know I have to do all these things.
>
> Jasmine: Yeah.
>
> Karina: You telling me is not gonna help me. I already know what I've got to do and if I don't do it, it's up to me.

Jasmine: Yeah.

Karina: We already have doctors on the medical team that will tell us. Do your exercise. Do your treatments. Do all that. Don't need that in the social worker.

Jasmine: Yeah

Karina: That's all I have to say on that.

Jasmine: Thank you, that's a good one. Yeah, so basically recognizing that you're a person who makes your own choices they need to respect that. And not pushing things on you when you clearly express your needs and they're not listening to your needs, so them listening to your needs and where you are.

Karina: (nodding affirmatively).

Diane (Sage): [The psychiatrist] told me, for example, we were talking about the dog. He said don't get a dog, just focus on your studies, and then think about the dog later on. So, I didn't like that.

Amelie: I just think that unless there's really a reason that your patient is in danger, it really briefly here I don't think that it's something you should force on them cause it doesn't really bring you anywhere anyways. In my personal experience, that's how it was. OK, cause they just don't open up, they don't. They just don't wanna talk about it. They might just want to keep it to themselves. I think that's something that the patient needs to do on their own.

Jasmine: So, … I definitely feel that not forcing anything on the client that they are not ready for … is definitely important for sure (106).

8. Feedback and Suggestions re: PAR Methodology: a) General Comments and Dissemination of Results; and b) Fostering a Sense of Community. Super-ordinate theme eight is divided into two subsets, based on the section of the Topic Guide: reflection questions on

methodology used in the research. The first subset reflects answers to questions 10 through 12, whilst the second subset evolved from observing the sense of community that developed between co-researchers engaged in PAR. This researcher shall elaborate on both subsets here.

8.a Feedback and Suggestions re: PAR Methodology - General Comments and Dissemination of Results. General comments from co-researchers regarding PAR methodology included: the benefits of the focus group format in terms of giving more "inspiration to talk;" appreciation for being asked for their input regarding what they "really need and want;" noting how this project has highlighted the connection between mental health and chronic illness where there had been a gap in sensitivity to this subject; and the requirement to "roll with the questions" for the good of the study (107, 108, 109). All agreed that by using PAR we were capturing what we were after in this study- developing A Patient-Centred Framework for Counselling and Psychotherapy with Persons with CF. Amelie and Alice speak to the benefits of a focus group format (110):

> Amelie: Yeah, I feel like just being connected with you guys here and having all your ideas thrown out and seeing how you guys think makes me feel a little bit less … like it gives me a little bit more inspiration to talk rather than just having them give you a questionnaire and fill up this question and go on with this study. I feel like having a group conversation is recorded and you're each kind of tossing ideas and meeting each other. I think that that's helpful for a study like that.
>
> Alice: Yeah, very much here that the more we participate, the more we all get out of it.
>
> Amelie: It's more personable. It's less there's like a sheet and here you go.

The conversation then turned to co-researchers' thoughts regarding sharing the patient-centred framework with other CF patients at the Ottawa clinic and requesting feedback from them before

finalizing it, as well as how the framework should be disseminated to have the greatest impact on counsellors/psychotherapists and patients. Regarding the former, there was a consensus to share the framework and elicit feedback from all CF patients for the following reasons: to "make them feel like they're not alone and get a different perspective;" to ensure they feel "inspired," validated and less judged especially if "they haven't had a lot of time to talk with other CFers or be a part of a group or just being in therapy period;" and to get a "CFers stamp of approval…to go about implementing this framework that's going to be used for all of us" (111, 112). These sentiments are encapsulated in the following statement by Sage, through her interpreter Diane: "It's gonna give a chance for any CF patient to share his experience and to see the result and to be connected to the group so that that would benefit everybody as well" (113).

With respect to the dissemination of the framework, co-researchers made several suggestions accordant with different target groups, for example, CF (RD) counsellors/psychotherapists versus CF patients. Regarding the former, medical conferences or "conferences for professionals" and journal articles were considered a good means of dissemination. Regarding the latter, conveying information at transition visits from the Children's Hospital (CHEO) or otherwise via pamphlet or resource package and creating social networks across CF teams had been considered to be most impactful (114, 115, 116). Jasmine summarizes these ideas as follows:

> Jasmine: I think all of those ideas are really good. I think a conference makes the most sense for the professionals and they can deal with that. But in terms of patients a pamphlet is a good place to start but implementing that into teams like across wherever CF teams are and communicating with one another and making those forums for us where we can

connect with one another and making that a part of even the framework of therapy in itself and in making that social network for us as well (117).

8.b Feedback and Suggestions re: PAR Methodology - Fostering a Sense of Community.

The experience of being in focus group one was ultimately positive for all co-researchers for many reasons, which fostered a sense of community. To begin, due to the risk of cross infection persons with CF (RD) are isolated from one another and this had been for many their first experience interacting with others with CF (RD) in any meaningful way. Being together by means of focus group interaction allowed for co-researchers "to talk together and connect in [their] experience," find "common ground" and conversely "gain perspective" as it highlighted differences between those at various stages along the spectrum of CF(RD) (118, 119). It also served to normalize their experiences, for example, in the words of one, "it's kind of cool being in a video call where you can see and hear people coughing like you … and feel free to just let it out" (120). Co-researchers in focus group one also supported one another when sharing difficult experiences, as in the instance of Karina, and her dilemma deciding between having a "child by you" or going on Trikafta. Witness, for example, the group engaging in empathy and mutual support after Karina shared her story (121):

Alice: No kidding, thank you for sharing it. No doubt that is one of the most complex problems with CF I've ever heard. Lots of layers.

Jasmine: Yeah. Thank you so much for sharing that with us and being vulnerable, really appreciate that.

Karina: Really just pours out (laughter). Well, I'm done. Somebody else can go now.

Jasmine: OK. Amelie?

Amelie: Yeah. Big hugs from my family to yours.

Karina: Oh (touches heart).

Amelie: So yeah. Now I feel like my struggles aren't so bad (laughs).

Karina: Don't feel that way Amelie.

Jasmine: They're all, they're all different. They're all different.

The outcome of being in focus group one was that co-researchers felt "understood, valued and heard" even while "talking about feelings is definitely not easy." This prompted Alice to state, "I have five new friends that completely understand me" and Sage to proclaim, "I feel honoured to know all of you" (122, 123). The sense of community fostered in focus group one prompted all to consider the possibility of participating in an online forum moving forward to continue to communicate with one another and to discuss an existing forum, CF Ties, which many had not been aware of (124, 125). Finally, others mused about formalizing forums as part of the patient-centred framework, making building and sustaining a social network "part of even the framework for therapy" (126). Jasmine summarizes this succinctly:

> Jasmine: So, it's almost like can get individual therapy, but here's the supports and connections, especially for those of us who are very isolated and don't have those supports. I think that's something important that could be implemented into this framework (127).

Summary Reflection Focus Group One. Whilst at times focus group one seemed stuck in the storming or encountering difficulties phase of group development, ultimately co-researchers moved through norming (developing cohesion), performing (accomplishing tasks) and adjourning (closure). This is due in part to the sense of community that developed, creating safe spaces for co-researchers with diverse backgrounds, knowledges, vulnerabilities, and strengths to disclose intimate details of their CF(RD) experience and support one another. Fostering a sense of community in focus group one had been due in part to PAR methodology, the experience of being

in a focus group with like others with a purpose or meaningful goal. The preparations to ensure that all felt "seen and heard" by way of co-facilitator training and pre-circulation of the Focus Group Participant Cheat Sheet no doubt also contributed to this outcome. The greater part of the sense of community that was fostered in focus group one, however, likely derived from an innate need to be connected and to be healed through connection, which persons with CF(RD) are deprived of due to the idiosyncrasies of their illness/disability. This basic need to connect in community is best described by Stephen Lazarus in the introduction to the collected reflections of Henri Nouwen (2021), whose ministry spanned from the 1970s to his work with L'Arche Daybreak alongside those with disabilities, "For Henri, community is a basic need and hunger of the human heart. We are created for community, but often we do not experience it…" (Lazarus, 2021, p. xiii). Nouwen also reflects upon community but brings in the idea of it being an important spiritual journey. On the back cover of the book, Nouwen is quoted as saying, "What an enormous, important spiritual journey it is when we discover that where our healing begins is where joy is rooted. Not in where you are different from people, but in where you are the same" (Nouwen, n.d. as cited in Lazarus, 2021). Likely, co-researchers in focus group one benefitted from both PAR and the spiritual quintessence of community. Through their efforts they developed the beginnings of The Patient-Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis.

8.1.2 Focus Group Two

General Characteristics of Co-Researchers. Focus group two took place on October 5, 2020, at 5:30 pm. Again, the focus group and preparatory meetings were held on MS Teams to circumvent cross contamination and infection from COVID 19. Whilst COVID had significantly impacted co-researchers in all realms of life their conversations on living with CF (RD) day to day

instead centred on fully six other subsets, which will be elaborated upon in the super-ordinate theme 1. Experience living with CF (RD) day-to-day, in the analysis of the super-ordinate themes which follows.

Co-researchers in focus group two were 39 years of age or older at the time of this study. In 2020, persons with CF were only "allowed" the life-changing medication Trikafta on compassionate grounds, meaning that their lung capacity had to be 40% or lower. On June 18th, 2021, Health Canada finally approved Trikafta for wider distribution in Canada for persons aged 12 and up and on April 20, 2022, for those six to 11. This means that co-researchers in focus group two would have grown up in a world where their life expectancy was considered shorter than is possible today. This has had implications for them in many respects. To begin, they had limited treatment options. Fully two co-researchers have had lung transplants, the only viable treatment at the time, and one co-researcher had been on the lung transplant list but was "happily kicked off it" after he finally was "allowed" Trikafta when his lung capacity fell below 30%. Other implications include the psychological impact of having had an incurable and "exceedingly life limiting disease as compared to today." The implications of "being on the high end of [their] life expectancy" and "having grown up in a different time" can be seen throughout the analysis of the super-ordinate themes and particularly in the following: 1.b Experience living with CF (RD) day-to-day-interpersonal relationships; 1.h Experience living with CF (RD) day-to-day- Trikafta (this magic pill); and 2.c Psychological impact of CF (RD) -not feeling good enough.

Focus group two is made up of six co-researchers (Jake, Marie, Kyle, Charles, Dolores, and Arianna) as well as our research assistant, Rebecca, who co-facilitated the group with Charles when only one co-researcher had volunteered. Dolores left the group early as she received a call at the outset that her daughter had been in an accident. We therefore have socio-demographic

information for Dolores, however, no further details regarding her experience. Once again, for the purposes of confidentiality all names, except for that of our research assistant and this researcher, are pseudonyms and have been agreed upon by co-researchers.

Co-researchers in focus group two in the icebreaker exercise introduced themselves as follows. Charles, "a proud father of two boys," was diagnosed "late at the age of 30" when he had gone through in vitro fertilization (IVF). His brother also has CF. Arianna, aged 41, was diagnosed at two weeks old and had been "a double lung transplant recipient in 2009 so [she] gets two birthdays." In the introductory exercise, she stated she was working at two places of business. Jake, 39, was diagnosed with CF "at either a week old or a few weeks old." He works for the government and 10 years ago "got a double lung transplant so, [he's] 10 years in." Kyle grew up in Eastern Canada, "worked for a computer company for 18 to 20 years and just turned 47." He had been on the double lung transplant list but started Trikafta in March which has been "a huge game changer." Marie, 40, "didn't even get to have a big party, so that's not fair," due to COVID. She was diagnosed with CF at age 29, six months after her son was born with Meconium Ileus (most infants with this bowel obstruction have CF) so it was a "double shocker." "It's been 11 years now that [they've] been living with CF."

Socio-Demographic Details. Please see Table 2 below for a visual representation of focus group two socio-demographic details, followed by a written summary:

Table 2

Focus Group Two Socio-Demographic Details

Name:	**Jake**	**Dolores**	**Marie**	**Arianna**	**Charles**	**Kyle**
Age:	39	40	40	41	45	47
Gender Identity:	Male	Female	Female	Female	Male	Male

Age at CF diagnosis:	1 month	30	29	2 weeks	30	9
Language:	English	English	French	English/ French	English	English
Living status:	Living with spouse	Living independently and with children part-time	Living with spouse	Living with spouse	Living with spouse	Living independently
Relationship status:	Married	Single	Married	Married	Married	Divorced
Employment status:	Full-time	Full-time	Full-time	ODSP	Full-time	Student
Education:	College Diploma	University: undergraduate	University: graduate	College Diploma	University: graduate	University: undergraduate
Are you a person with (CF18-30; CFRD; CF39 +; Other):	CF39 +; CFRD; Double lung transplant	CF39 +	CF39 +	CF39 +; CFRD	CF39 +	CF39 +
Do you identify as a person with Non-visible illness/disability ?	Yes	Yes	Yes	Yes	Yes	Yes
Previous Counselling and Psychotherapy experience?	No	Yes	Yes	Yes	Yes	Yes

Ages of co-researchers in focus group two ranged from 39-47. In terms of the gender identity of co-researchers, three identified as male and three as female. Again, Dolores did not remain in the group, therefore the gender compliment was three males and two females plus Rebecca, female, as co-facilitator. Age of CF diagnosis fell in the early diagnosis range for two of six co-researchers, two weeks and one month respectively, with fully four being diagnosed later at

ages 9, 29 and two at 30. This is an unusual ratio of early to late CF diagnosis as most persons with CF are diagnosed from infancy to two years of age. This might explain why this became a topic of conversation and will be expounded upon in super-ordinate theme 1.c Experience living with CF day-to-day - early and late diagnosis. Co-researchers cited English or English/French as their primary language with one, Marie, citing French, for which she apologized and remained "slightly self-conscious." Co-researchers mostly resided in the greater Ottawa area. Living statuses included four co-researchers living with their spouse, one living independently and one living independently and with children part-time. Four co-researchers identified their relationship status as married with one divorced and one single. Five of the co-researchers identified working or going to school full-time with one, Arianna, citing her employment status as ODSP. This is curious as in the icebreaker exercise, she mentions working at two places of business. It is unclear why the discrepancy, although persons on ODSP are restricted in the amount of income they could garner, and she might not have wanted to state that she was on ODSP and working in a written format, on the socio-demographic questionnaire. All co-researchers had either a college diploma or university degree with two having completed graduate school, a highly educated group. This may be due in part to many having a late diagnosis and therefore potentially a milder form of CF or a result of higher socioeconomic status and other positive determinants of health. In terms of identifying with one of the three groups in this study – CF aged 18-29, CFRD, CF aged 39 + - all marked CF39 + with two also indicating CFRD. It is important to note that for the purposes of this study the two co-researchers citing both CF39 + and CFRD, Jake and Arianna, were placed in focus group two so that there would be an even distribution of co-researchers per focus group. It was also thought that they would have more in common with co-researchers in focus group two than focus group one,

who were considerably younger in age. Crucially, all six co-researchers marked yes to identifying as someone with a non-visible illness/disability, with some elaborating as follows:

> Jake: "I also have other non-visible illnesses/disabilities -diabetes, osteoporosis, fatigue."
>
> Dolores: "I have other non-visible illnesses/disabilities, for example, depression and anxiety that come with CF."
>
> Marie: a) for income tax purposes (and other government programs); b) at work (pre-COVID, I negotiated with work to be able to work from home for two hours in the morning to do my treatments while working. During COVID, I am working from home until further notice).
>
> Charles: "My older brother also has CF."
>
> Kyle: "Yes, I have cystic fibrosis and people are not able to notice the difficulty walking, difficulty breathing and most times the amount of coughing."

Finally, all but one co-researcher in focus group two, Jake, marked yes to having had previous experience as a client/patient in counselling and psychotherapy, stating that instead, "when [he] has problems [he] mostly talks it out with [his] wife." The following are other co-researchers' response elaborations:

> Dolores: "For approximately a decade and this time for two years now with the same psychotherapist."
>
> Marie: "I have consulted with a psychologist two times before as a CF late diagnosis and as the parent of a child with CF."
>
> Charles: "I am having my first experience in counselling and psychotherapy. Approximately nine months."

Kyle: “Yes, I have seen a relationship therapist about six times and a therapist at the cystic fibrosis clinic for several months.”

Arianna: “I had been seeing a psychologist after transplant to deal with survivor’s guilt.”

PHQ-9 Scores. Fully all co-researchers in focus group two scored in the none-minimal (zero-four) to mild (five-nine) range on the PHQ-9, with the highest score being seven and the lowest zero. Only four co-researchers checked off an answer regarding the degree to which their problems “made it [difficult] to do work, take care of things at home, or get along with other people.” Of those, two marked “not difficult at all” and two marked “somewhat difficult.” It is worth noting that one of the co-researchers observed that his score “would have been lower by four” had he not been “having a hard time with [his] abdomen” and therefore marked “occurrence more than half the days” to two somatic questions three, “Trouble falling or staying asleep or sleeping too much” and four, “Feeling tired and having little energy.” No co-researchers answered affirmatively to question nine, “Thoughts that you would be better off dead or hurting yourself in some way.” Due to the low scores of co-researchers in focus group two on the PHQ-9 and no affirmative answers to question nine no further intervention had been warranted on the part of this researcher.

GAD-7 Scores. GAD-7 scores for co-researchers in focus group two were like that of the PHQ-9. All co-researchers scored in the none-minimal (zero-four) to mild (five-nine) range, with the highest score being six and two co-researchers scoring zero. In terms of the impact of their problems, the degree of difficulty in the various life domains, of those who responded two marked “not difficult at all” and two marked “somewhat difficult.”

Group Dynamics. There were two notable group dynamics in focus group two: 1) the sense of community that developed amongst co-researchers, which this researcher will elaborate

upon in super-ordinate theme 8.b. Feedback and suggestions re: PAR methodology -fostering a sense of community; and 2) a group dynamic involving two interconnected existential themes: individual identity and truth (Sbarby et al., 2019). In the first instance, there is a disparity between how one group member, Arianna, self-identifies with her illness and how others see their own identities in relation to CF (RD). In the second instance, there is a discrepancy between how Arianna views truth, as literal, versus that of the others, who view truth as a subjective phenomenon. The way that Arianna, Charles, Jake, Kyle and Marie perceive their selves in relation to CF (RD) as well as how they view truth impacts their behavior, for example, disclosing or concealing their illness, or being "preachy" versus allowing for ambiguity. While not overtly stuck at the storming stage of group development, several co-researchers chose not to embellish upon Arianna's answers throughout group and took exception to her position in their feedback after group, with one stating "I did not appreciate her coming off as expert on CF and approaching other parents as though everyone's the same and she knows what's best for them." To illustrate the difficulty focus group two encountered, a few exchanges are outlined, with brief introductory comments and a summary statement:

Arianna saw herself as "the poster child for CF" growing up in part because her mother taught her that her illness would not define her or hold her back. She disclosed her CF to others and was very proud to "have CF" because it made her an individual:

> I had so much energy to burn that I would just go and I would run and I would run for like three or four hours…. so, they would look at me and they're, Oh, you're like the poster child of CF in Ottawa … I love the fact that I had CF because I was an individual. Nobody else had what I had. Like ha ha, I've got this. You don't. Nah. I'm better than you… I never saw it as an excuse to not do something I just did it…But yeah, I think it has a lot to do with

> the way you're raised. Like my mom wasn't like they gave her pamphlets. When I was first diagnosed…my mom took the pamphlets threw them in the doctor's face…This isn't going to define her … I was upfront about my CF, with everybody, all my friends knew everybody knew my teachers knew. Like I said I wasn't afraid to tell people (1, 2, 3, 4, 5).

Contrast this with Charles, Jake, Kyle and Marie who struggled with their CF (RD) identity or did not identify solely with CF (RD) and respectively thought of themselves as "a burden," "inferior to others" or "self-conscious and ashamed," like they were "bothering people" and "not feeling good enough." This meant that they concealed their illness:

> Charles: I'm carrying bugs. I'm making other people sick. I'm a burden so to speak. In some respects, I was …. I'm taking it really you know, sort of sharing with everybody your condition. I've been somewhat secretive of it since diagnosis. My family, you know those that are my close friends know of it, but it's not something I am (6, 7).
>
> Jake: I felt like a burden for most of my youth, that I was inferior to others because I had CF…. So, this is something I felt throughout most of my youth. Ah, that I was inferior to other people because I had cystic fibrosis as in physically like I couldn't keep up with them…. I remember feeling very self-conscious about it and I was very ashamed. I had cystic fibrosis like I didn't want any of my peers or friends to know (8, 9).
>
> Kyle: I did feel like I was bothering people as a child… I'd make sure that a loud noise came on before I started coughing or I was always sitting next to the aisle so I could leave at a moment's notice to go outside (10).
>
> Marie: In my case, I would say that naturally I'm a perfectionist, so CF just adds to my feeling of not being good enough … it took me five years to self-declared or just to tell my colleagues that I had CF because we were five fighting for the same job for five years, so

> I worked my butt off sorry and I did everything I could because there was a culture at one time where they were trying to get rid of people with the health issue. Of course, they were not saying it aloud, but I was advised by colleagues not to say anything (11, 12).

After several similar exchanges, the one that follows is perhaps most representative of the dynamic in group two. Given Arianna's positive CF identity and the way she navigates the world, she feels that others should follow suit. There is no room for equivocality here. She has decided that her purpose is to "educate new parents with kids with CF." Co-facilitator Charles moves on rather than embellish upon her point. It is notable that Arianna has some insight into the dynamic in the end, noting that she "just rambled on" (13):

> Arianna: I think now I wanna educate the new parents with kids with CF because a lot of those parents now there, so their micro managers. They're like OK you have to do that. You can't play. I had one lady say to me my son can't play hockey because of the bacteria that grows in his equipment. I looked at her and I said, do you wanna bury your child and she's like you can't say that to me. I said yes, I can because one, I have CF and two, I was active my entire life…it's not the end of the world unless you want it to be.
>
> Charles: Thank you Arianna.
>
> Arianna: I just rambled on there.

Summary Statement. At first glance it is difficult to discern the dynamic between Arianna and the other group members. Her exchanges are littered with disagreeing statements, for example, when discussing treatment protocols she asserts, "so I was literally the polar opposite of Jake." This had the effect of "running certain people down" and creating distance, although the group did come together with Arianna eventually stating, "Everybody in this little group I love everybody." Upon analysis, it is likely that Arianna's interactions with others reflects her complex relationship

with CF as disability. For example, she defines herself as "the poster child for CF" and revels in this identity in so far as it makes her unique, however, as will be elaborated upon, she refuses to be limited by her illness in terms of it signifying any weakness or frailty. It is possible that those in group who disclose vulnerability trigger existential anxiety in Arianna and, fearing her own decline or loss of autonomy, she pushes them (and her own vulnerability) away (Lingsom, 2008; Stone, 1995). In this sense she exemplifies so many with progressive and/or acquired non-visible illness/disabilities, such as CF who fight against being dis-abled and experience internal conflict (Fitzgerald & Paterson, 1995; Pachankis, 2007; Varilek & Isaacson, 2020). As Arianna's health declines she must somehow come to terms with her sameness, the reality that she too is grappling with a dis-ability, but she is not there yet. This suggests the words of Nouwen (2021):

> But I found myself hiding my vulnerable side so I could compete better… What I would like to say is that there is a whole different definition of who I am. And that is: 'I am the sameness I share.' I'm not the difference I make but the sameness I share (Nouwen, 2021, p. 100).

Super-ordinate Themes. The following is an analysis of the eight super-ordinate themes and subsets (below) for focus group two. Relevant quotes will be highlighted along with the corresponding emergent themes to capture the depth of the experience of co-researchers. A summary reflection will follow:

- 1. Experience living with CF (RD) day-to-day: a) symptoms and treatments; b) interpersonal relationships; c) early and late diagnosis; d) impact on career; h) Trikafta (this magic pill) and i) CF Camp;
- 2. Psychological Impact of CF (RD): b) isolation from others with CF; and c) not feeling good enough;

- 3. CF (RD) as a non-visible illness/disability: b) concealment vs disclosure (treatments and identity);
- 4. CF (RD) and sense of self/identity;
- 5. CF (RD) positive aspects and meaning and purpose in life;
- 6. Observations and recommendations: a) CF (RD) counsellors/ psychotherapists-attitudes, knowledge and skills; and b) CF (RD) doctors, nurses, and all allied health;
- 7. Counselling and psychotherapy experiences: a) helpful experiences;
- 8. Feedback and suggestions re: PAR methodology: a) general comments and dissemination of results; and b) fostering a sense of community.

Experience Living with CF (RD) Day-to-Day. Focus group two co-researchers centred their discussions on living with CF (RD) day to day on fully six themes or subsets: a) symptoms and treatments; b) interpersonal relationships; c) early and late diagnosis; d) impact on career; h) Trikafta (this magic pill) and i) CF Camp, which this researcher shall elaborate upon here:

1.a Experience Living with CF (RD) Day-to-Day - Symptoms and Treatments. Co-researchers in focus group two shared that living with CF (RD) means having a unique experience to others with the illness, regarding the degree to which it impedes one's day to day functioning and the amount of time spent on treatments, particularly when young. However, many commonalities do exist, for example, declining health, the unpredictability of the illness, and in some instances, having no recourse but lung transplantation which can be "hard to wrap [one's] mind around" (14). Jake, Arianna, and Kyle speak to their disparate experiences of having CF when young:

> Jake: I couldn't keep up with them as far as you know, running was concerned or other activities … but this was something as a kid… And I found out later on in life, that not all

cystic fibrosis patients we all had it varying degrees. Some of us you only had to do five minutes of physio a day and some of us needed to do two hours (15, 16).

Arianna: I did 20 minutes of physio a day, so I was literally the polar opposite of Jake like I did everything I would go running at 2:00 o'clock in the morning cause I had so much energy to burn (17).

Kyle: I guess just say that I'm in a similar boat to Arianna and just in the sense that as a child like Arianna I was able to play a lot of sports and do things my parents put me in (18).

Inevitably one's health declines and this seems true regardless of whether one had an "easier" or "harder" childhood experience with CF. For Jake, Arianna, and Kyle this meant having to adjust both physically and psychologically. For example, adapting to longer treatments, reduced stamina and increased symptoms which could make one "become a recluse:"

Jake: The last 10 years before transplants between 20 and 30 it wasn't unusual for me to wake up in the morning I did an hour of physio before going to work. And then coming back after work eating maybe napping for a bit doing another hour of physio so I did about two hours of physio per day (19).

Arianna: I didn't want to go outside of my bubble. All the activities I would do everybody knows what I have and they're like OK well if she needs to sit out she needs to sit out. As I got older, and I started to get more sick because I became less active. I think. I became a recluse. Yes, because I would cough more, and it would hurt more…. when you cough to the point where you have, like, no air left in your lungs and you're ... Eh Eh Eh (20, 21).

Kyle: OK, can't play basketball anymore so I organized a pickup game with friends once a week where I can just hop off on the fly and then after a while like last couple of years, I would bring my oxygen tank with me…So obviously it was my lungs that was bad. And

> then like Jake in later life so between around 35 to 46 until Trikafta I was pretty much doing, took about an hour and half in the morning of coughing straight like coughing. Getting up getting out of breath catch my breath….and I decided that I'm going to quit work and focus on doing exercise (22, 23, 24).

Finally, maintaining one's health can be arduous and, even when diligent, CF (RD) can be "sneaky," with health declining with no apparent notice and seemingly beyond one's control. This underscores the fluctuating nature of the illness:

> Marie: The big difference for me is the two to three hours of treatments that I have to do every day because, although I have a very good lung function for 40 years old it takes a lot of work to keep it there so I can't stop … CF is sneaky as all of you know, and I can think that I feel super good and the next day I'm coughing up blood and I'm in the in the hospital. So that happened to me recently. I was like wow it's been months without antibiotics I'm feeling awesome and then poof. Hemoptysis and in the hospital for a weekend so that's CF for you (25, 26).
>
> Jake: Marie I relate to the whole you know CF being sneaky that one day everything is going fine and you think you're on top of the world and next you're coughing blood and you don't know why so that was very discouraging. It sometimes cause you think you're doing so well, and you are taking two steps backwards (27).

1.b Experience Living with CF (RD) Day-to-Day- Interpersonal Relationships. Co-researchers in focus group two largely spoke about the impact of CF (RD) on their interpersonal relationships in terms of concealing the extent of their illness from family to keep them from worrying, the difficulties of finding a partner when one has a life limiting illness and the profound implications for their partners once they are in committed relationships. Kyle delayed telling his

parents about his declining health until he was put on the double lung transplant list in order to put off their inevitable response, "they'd realize okay it's bad so they'd get worried" (28). Marie is so concerned about worrying her husband and family regarding her CF that she regularly "self-censors" and speaks quietly in the focus group so that her husband won't hear what she is sharing:

> Marie: I tried to tell my husband nothing about my CF and like I'm speaking quietly right now because I don't want him to hear. But because I don't wanna worry him so I self-censor all the time. My parents and my sister are worry warts. So … I know that if I say that no I'm not feeling well or something is wrong, they're going to be worried about me (29).

Kyle speaks about the difficulty of dating when one has CF, particularly putting it off for fear that he could not keep up, engaging in machinations to "work around it," and not feeling "ready or mature enough" to manage both his own and his partner's expectations regarding having a family. Jake talks about the difficulty of dating and then finding a life partner when one has CF(RD) because "it's always a bit of a stigmatic," finding someone who will "stick by you." Both Kyle and Jake's narratives are closely associated with a confrontation with death for themselves and their life partners. Fortunately, Jake now has been "happily married" for 10 years:

> Kyle: And relationship wise. Yeah, I always said no to university and high school for dating just because I didn't think I was able to keep up doing things. Like, once we want to go for a walk or hike, I knew that I wouldn't be able to do it as easily. I might have to stop and take pictures or tie my shoelace or point the thing out and look something up on the internet. Stop and catch my breath. Yes, a lot of working around it. And then as well some of the people I dated wanted to have kids I couldn't have kids without some sort of intervention and then as well I felt that having a child while having CF having to do an hour and a half

to three hours a day for physiotherapy medication and stuff. I didn't feel like I was ready or mature enough to be able to try that so relationships didn't work out (30, 31, 32).

Jake: Yeah, I second what Kyle said relationships are tough, especially my 20s when you want to settle down with someone serious it's always a bit of a stigmatic cause it's like but you know, I know I know you really like me, but I could die someday soon. CF you don't know what's going to happen, so, if they want to have a long-term plan involving family and kids well, I can't have kids by the way so it was very tough to find the right partner that can understand stick by you through all this and take a chance on you per say…. I did find the right partner and we are happily married now it's been 10 years and I really appreciate her, and nothing will ever change that, but that's just one of the true realities (33, 34).

Finally, Arianna and Kyle expound upon having to have existential conversations regarding life and death when one has CF and has finally found a life partner:

Arianna: But if you can find the right person, but they have to understand that … you may have to move on without me at one point. And we have these conversations every year like OK, we're one year past another transplant birthday. So, we have to consider this because, as you get older in transplant life you're living your lifeline it deteriorates. Huge (35).

Kyle: ...my girlfriend, she grew up in a war zone for four years. Her father was killed … so there's a lot of trauma there…And then with my coughing and … it was a trigger for her that, you know, I'm going to die. So just like her dad and other friends and stuff (36).

***1.c Experience Living with CF (RD) Day-to-Day - Early and Late Diagnosis*.** Many co-researchers initially spoke about their early or late CF diagnosis variously at two weeks, a week old or a few weeks and at ages 29 and 30, in the introductory icebreaker exercise (37, 38, 39, 40).

Co-researchers who had been diagnosed later subsequently elaborated upon this point referencing their "milder" or idiosyncratic symptoms, being misdiagnosed, and feeling grateful that "finally people put things together." Being misdiagnosed is typical for those with a late diagnosis of CF who may have a milder form and do not present "like a textbook example." This sometimes means years of delay in getting the proper treatment and having to cope with features of an acquired non-visible illness/disability inclusive of psychological, identity and spiritual issues. Marie and Charles speak to some of their experience here:

> Marie: I have 20 years 29 years without knowing I had CF, but it doesn't mean I didn't have symptoms of course, but they were milder than I know I can compare because my son has CF and he has a more typical, you know double Delta F 508. I have a milder gene in a more regular one, so I had yeah issues. I was diagnosed with asthma but coming from a small town … I went to see a lot of doctors, but they didn't get a lot of very good diagnostics over the years, so it took his birth to finally people putting things together and leading to my diagnostic (41).
>
> Charles: I was diagnosed at 30. I really didn't show any symptoms. Probably till a few years after that I had a lot of sinus problems and my grandfather had sinus problems and I'm very fortunate. But I do have my challenges that's for sure. I do. I can relate to thinking about you know, I'm sick … I was not able to have children, I found out about that time period … but very fortunate to go through IVF (42, 43).

1.d Experience Living with CF (RD) Day-to-Day – Impact on Career. For many co-researchers CF (RD) has meant having limitations on their career because they have had to decide upon employment that is realistic and sustainable in terms of their physical limitations and benefits provided to cover the cost of medications and treatments. This has caused them to change course

in career, “taking you to places you weren’t expecting,” and has had both psychological and physical implications. Kyle, Jake, Arianna, and Marie speak about having to find a job that has “good health care and life insurance” and “flexible hours,” the difficulty of finding a job “that covers medical insurance in a small town” and having to curtail one’s expectations, which could have a negative impact on one’s identity, as is evidenced in Arianna’s statement, “you’re a liability:”

> Kyle: I guess for me with career it was staying in a career that had a good prescription drug plan and life insurance and one that afforded me flexible hours so I can go to work at 7:00 o'clock or if I had to do extra physio but didn't because I woke up coughing then I can go in at 9:00 or 9:30 or 10:00 stay a little longer as well … Not necessarily something I wanted to do. I wanted to change career for a number of years, I wanted to go into either EMT or research. But those weren’t available. You can't be an EMT if you have bad lungs you can't do CPR. Or more susceptible to bacteria if you're in a hospital setting (44).
>
> Arianna: So, it’s hard in a small town to find a job with benefits and pensions and stuff like that, so I’m on ODSP. I get my disability because I can’t find a job that’ll give me all these medical things that I need and to pay…. And then my dream was to be a firefighter and I passed those tests and then as soon as I get to the medical, they’re like eh you’re a liability (45, 46).
>
> Jake: And as for jobs well after I graduated from college, I would have liked to continue to university, but I had an offer … to work full time and I really wanted those health plan, health care and pension. So, I took it. If I could do it all over again, I was healthy, I probably would … yeah, the party takes you places you weren't expecting (47).

Finally, Marie reiterated that vying for her government job was essential to obtain the benefits for herself and her son but came at a great personal toll:

> Marie: I it took a big toll on my mental and my physical health, but I wanted the government job with the benefits for my son. And for myself. Finally, did it (48, 49).

1.h Experience Living with CF (RD) Day-to-Day- Trikafta (This Magic Pill). Being that focus group two is made up of co-researchers 39 years of age or older, they did not have access to some of the newer treatments and two, Arianna and Jake, have had double lung transplants. There are limited studies, however, it does not appear that Trikafta after lung transplant is well tolerated or will have significant benefits (Cystic Fibrosis Foundation, n.d.). One co-researcher, Kyle, had been on the lung transplant list and was allowed Trikafta on compassionate grounds at the outset of its release in Canada, close to the time of this study. Arianna and Marie begin this discussion by referring to Trikafta separately as "a miracle" and "this magic pill." For Marie, being on Trikafta would mean more freedom and focusing on what matters, bringing more meaning in life:

> Arianna: What's this? It was like it's the craziest thing that like seeing the advancement in CF from when we were kids to now and even the medication like Trikafta. Hello, where was that 20 years ago when I needed it and just like I'm still envious of the people who get to try it and it's actually working for them cause I could just imagine for us who have had transplants. If we had that back in the day, we wouldn't have transplant because this drug is just like a miracle (50).
>
> Marie: But if there was a magic pill like hopefully Trikafta (air quotes) that would mean that I can I don't have to do all of that anymore. And I can focus on the things that I love more than doing treatments. I would definitely take it (51).

Jake and Arianna then share that they hope their struggles and participation in drug trials have helped others. Jake mentions feeling both "grateful" and "envious:"

> Jake: I'm grateful but I'm also envious but I like to think that all the struggles that we went through helped somehow.
>
> Arianna: Yeah.
>
> Jake: Generation. That's how I feel about it. Truthfully.
>
> Arianna: Yah. I don't know if you took part in any of the trials for any of the medications or anything, but I did a couple of them and I'm like I don't feel any different I have a placebo blah blah blah but you never know (52).

Finally, Kyle "sheepishly" shares his experience on Trikafta, "as the others didn't have the same opportunity." Being on Trikafta has been transformative although requires some adjustment:

> Kyle: I got Trikafta in March and it's been a huge game changer for me. Now back into university, I'm doing biomedical science. So, I'm doing some research into actually phages in some viruses to kill like Pseudomonas Aeruginosa. It's been a huge difference in lifestyle since Trikafta … Trikafta has changed that now for me to a certain extent … like walking upstairs has been easier now, and I won't be coughing if I'm working in the lab … And … before Trikafta everything was normalized like coughing for an hour and a half in the morning or throughout the day was just part of life I just dealt with it … Just curious about how [Arianna and Jake] feel not having to cough every morning (53, 54, 55).

1.i Experience Living with CF (RD) Day-to-Day- CF Camp. The last topic that captured co-researchers' attention regarding living with CF (RD) day-to-day was their experience at CF Camp. Those that had been diagnosed as having CF at a young age, Kyle, Jake and Arianna, all "tried it." The fact that they had attended CF camp is indicative of their later age as CF camp has

since been determined to be “a mistake” and a “super spreader event” that caused many children to be infected with bacteria such as Cepacia which produced pneumonia. Whilst Kyle and Arianna initially wanted to go to CF camp, they then felt “unworthy” and “cried to their parents” to go home, respectively. Kyle seemingly felt too well compared to the other children with CF as did Arianna, but he also did not feel like he could keep up with his friends at home, so betwixt and between:

> Kyle: I wanted to go back the following year, but I really felt bad going back to camp because I was able to do more stuff as a kid than the other kids there, so I didn't really feel like I was worthy of being at CF camp and then when I'm outside and playing sports with friends feeling like I couldn't keep up (56, 57).
>
> Arianna: And I begged my mom to go and she's like. Eh, I don't know I don't think you should go. And I was like I wanna go. I wanna go. I was there for two hours, and I was crying. I wanted to go home. Because these people were so much sicker than I was (58).

Jake, on the other hand, had a very positive experience, enjoying being amongst peers and finally feeling like he belonged. It is worth noting that Jake struggled with poorer health when he was a child than Arianna and Kyle and therefore it fits that they felt unworthy and incompatible whilst he no longer felt alone:

> Jake: One summer my parents were asking to send me and said, OK, I'll send you for two weeks. So, I ended up going for two weeks and it was a lot of CFers we were maybe six, our cabin was six boys bunking. And you know it was a lot of fun. It was two weeks and you're with your peers and you all do physio at the same time, you're all eating together and stuff, and you just kind of feel that you belong …Oh you know I'm not alone (59).

Unfortunately for many children including Kyle, Jake and Arianna, CF camp was an ill-fated endeavor, with Cepacia rampant, long since abandoned (60):

> Arianna: But yeah, the camp it was a lot of fun but Cepacia was rampant in the whole thing and we were tested for a long time after that just to make sure we didn't have it. One of my good friends caught Cepacia at CF camp and he has since passed away. Yeah, it was ridiculous.
>
> Jake: But it turns out it eventually got shut down and it was revealed it was…. a UK experiment. It was funded by the UK and they wanted to see how CF kids interact with each other if they were spreading ... if kids with CF in close proximity would give each other different bacterias and stuff, and I remember one of my kids in my bunk developed pseudomonas. I don't know how I didn't get it. But one of them did. He didn't have pseudomonas before there or was it Cepacia.

Finally, while initially camp had been a positive experience for Jake, it has had a negative impact on how he views the world to some extent, causing him to feel "paranoid" and "a bit of skepticism." Arianna may now feel the same:

> Jake: But it's things like that that make me very paranoid.
>
> Arianna: Yeah.
>
> Jake: Because I found out that oh this really nice thing that was offered was actually a UK funded experiment. They weren't doing this with their own kids they were doing it with Canadian kids innocent. So, there's a bit of skepticism involved in a lot of things I do from now on like that's the kind of shapes who I am today right (61).

***2. Psychological Impact of CF* (RD).** The super-ordinate theme psychological impact of CF (RD) for focus group two is divided into two subsets: b) isolation from others with CF; and c) not feeling good enough, elaborated upon here:

***2.b Psychological Impact of CF (RD) - Isolation from Others with CF*.** Again, one of the most difficult psychological impacts of having CF is the fact that one cannot interact with others with the illness because of the risk of cross-infection. Even before scientists discovered this reality, for example, when co-researchers in focus group two were children and attending CF Camp, they had been kept apart in school settings and in the community perhaps because caregivers were concerned that this was so. Arianna talks about finding out that she was not the only one in her hometown with CF when she was 13, yet they were still not allowed to get together. Adolescence is the time for the healthy exploration of identity; however, Arianna was not able to be with her peers and compare herself to them. She had been told that she was the "poster child for CF in Ottawa" and concluded, with no other reference point, that she was "just like everybody else." Here she observes that even "cancer patients can get together" and criticizes the practice of isolation from others with CF as "ridiculous:"

> Arianna: I'm like OK for the longest time I thought I was the only one in my hometown who had it and then I found out when I was 13 that there were like four other people in my town that had it. I'm like why aren't we getting together like this was way before we couldn't talk to each other and like it was like a bad thing to get together. Now we can't be in the same room together, which is ridiculous. Like cancer patients can get together and they're all like bug transferable like we are, but for us it's just 'cause I had nobody to compare it to. I was just assuming I was like everybody else (62).

Later in the focus group, Arianna and Marie discuss how quickly "reality is changing" and the potential benefits of being in contact with others with CF. Mainly they could learn from one another about "things that work." This is in stark contrast to currently not being able to "talk in the doorways at clinic:"

> Marie: Reality is changing … quicker than the textbooks about CF, so having contact with us and maybe with other patients around the world. I don't know, but you know it's always to me, it's more than textbook knowledge. It's the contact and also it's very rare anyways for me that I'm in contact with other CFers … but I would definitely be happy to consider what works for others (63).
>
> Arianna: Hey, maybe we can tone this down or maybe this is a side effect that hasn't been listed of this medication, but I think group discussion that we're having now is great because if you got people like minds going on at the same time and this is how they tried to deal with it and maybe this will work for you too. So, I like this because we can't talk to each other. We can't even like talk in the doorways at clinic or anything (64).

2.c Psychological Impact of CF (RD) - Not Feeling Good Enough. The psychological impact of CF (RD), of not feeling good enough, permeated the conversations of co-researchers throughout focus group two. For example, Charles expressed that he felt like "a burden" because he was "carrying bugs" and later conceded that there are "certainly some mental aspects there that I'm faced with as a challenge" which result in his "being secretive" about CF (65, 66). Jake shared that he felt like a "burden," "inferior," "self-conscious" and "very ashamed" of his CF growing up and continued that he "does not know why psychologically this happened" (67, 68). Kyle felt like he had been "bothering people as a child," went to great lengths to hide his coughing and later marvelled when he got his driver's license because people with "diagnosis like mine one guy in

the bed next to me died" (69, 70). He also expressed feeling guilty for having to use government services for a time, "feeling bad doing it" until he told himself that he had been working for 20 years, paid his taxes and would again contribute once he "got better" (71). Marie epitomizes the sentiment of the group when she overtly states that CF adds to her "feeling of not being good enough." The combination of having CF and being a perfectionist has meant that she has often felt like she is falling short at work and in her parenting, which has had a negative impact on her mental health. Poignantly, she concedes that always feeling like she should "produce more" has caused her "mental issues made worse by CF:"

> Marie: In my case, I would say that naturally I'm a perfectionist, so CF just adds to my feeling of not being good enough … So as a mom, for example, if I'm tired or I'm sick, I always feel like I'm not doing enough with my son, especially because he also has CF. So, I want him to move. I want him to do all kinds of things and … like I always want to do more but I have to realize that sometimes I have to take time for me also to do my treatments and just rest. So that's part of my life and it's not always easy to … accept and it's the same thing at work because in my field Uh exercising and things like that are not. It's pretty much seen as a waste of time. I should always be researching and writing articles and books. So, I do exercise a lot. I love it. And it made a huge difference since my diagnostic, so I do it anyways. But I always like in the back of my mind is always a little voice saying like you should be producing more you know. So it's something that's always been with me, but CF just makes it worse. So, I would say that it's one of the big like if I look into mental issues that come with CF for me that that's a big one (72, 73).

Finally, Arianna concludes the theme of not feeling good enough by expressing that she has "felt bad" and has had "mental issues," because of survivor's guilt at having had a lung

transplant. She later states that she did resolve this to some degree by "sending a letter every year" to her donor's family:

> Arianna: But I did have one psychiatrist in my hometown that I used to go see after transplant to deal with my survivor's guilt. I had it pretty bad for about three years. I could not wrap my head around the fact that this person chose to donate their organs when they passed on…I'm seeing her for my mental issues that I'm having because I feel bad that I'm alive. This person's dead (74).

3.b CF (RD) as a Non-Visible Illness/Disability - Concealment vs Disclosure (Treatments and Identity). All co-researchers in focus group two first acknowledged that they had a non-visible illness/disability in their socio-demographic questionnaire and then elaborated upon this theme, as it relates to concealment versus disclosure of CF (RD) in the realms of treatments and identity. Kyle shared examples of being treated unfairly because of his illness in academia by a fellow student, and in the workplace by colleagues, and in so doing personified the castigation of "the alien other" (Stone, 1995, p. 421). When he finally disclosed his illness at work this elicited health-related stigma, an unsympathetic response, and ultimately, understanding (Oliver et al., 2014):

> Kyle: I ended up leaving probably about four university exams because I'd been coughing and the person behind me would be like, will you shut the fuck up stop coughing … and then throughout work you know is if I was coughing you get the comments that you should stop smoking or then that person I don't smoke I have asthma and then after a while OK, I got CF. One person actually said what do you want me to feel sorry for you? … Then you have some coworkers if they see you coming in late cause you're doing medication that day a lot and you can see they go up to you for coughing and they say Oh you've got bankers hours. Then you get sick of hearing it enough times and it's like then it's like well

> spent two hours this morning coughing. I'm out of breath. I needed an oxygen tank to walk to work today. And then they're understanding (75, 76).

The fear of being devalued caused some co-researchers to conceal treatments or avoid attending to their bodies, which negatively impacted their physical health:

> Kyle: I'd go to work and hide in the stairwell with my little compressor or my antibiotics like TOBI Podhaler and stuff. Do it in the stairwell. Make sure nobody's around cough up and then go back to work for a bit. So, I'd do that with my smoke break in the morning for 15 minutes in the afternoon…. So, and other times, I found that like if I went out with friends, I had to do medications. I probably should have taken them with me but it's hard to do around them. So, I come home and be tired and I'd skip it (77, 78).
>
> Marie: So, but at work with three other people in my spot that would be very difficult to do Pulmozyme or Saline and like it's not realistic …. it's also really easy to uh just push too much and get worse because no one knows you're sick (79).

Marie and Charles discuss the dilemma of concealment versus disclosure of CF at work, with the former referring to it being "a two-sided thing." Here, Charles agrees that it could be a "delicate balance," there is a desire to push beyond one's limits but then health can take a toll:

> Charles: Hey, I can relate to that it can be a driving force, sometimes for me as well. It's that it is a delicate balance in… You know you have something to prove to yourself and you feel like … health can take a toll for sure (80).

The dilemma of concealment versus disclosure of CF (RD) not only affected the realm of treatments but also identity, how co-researchers choose to see themselves and identify themselves to others. For example, Jake did not want his "peers or friends" to know that he had CF (RD) and therefore passed it off as "asthma or just allergies" for fear that they would judge him as harshly

as he judges himself (81, 82). Charles had always been secretive about his diagnosis and "taking a hospital break" as he owns his business. He doesn't want his team to think of CF as synonymous with who he is stating, "it's not something I am" (83, 84). Kyle concealed the severity of his illness with family and at work until he had no choice but to disclose because one requires a designated support person to be on the transplant list. He chose concealment over disclosure not only because he did not want to worry family, but he also did not want to be defined by his illness (85). Marie took "five years to self-declare to colleagues" that she had CF waiting until she had achieved her professional goals proving that she was more than CF (86). Arianna had always been "upfront about her CF," disclosing her illness to everybody including prospective partners as it was an integral part of her identity which set her apart (87).

Finally, many co-researchers had come to the conclusion that being more open about their illness, disclosing CF (RD), was "not necessarily a bad thing" in that this had promoted better understanding, made accommodations possible, "normalized it" and helped promote compassion for difference (88, 89, 90, 91, 92, 93, 94). This is in alignment with many in the field of disability studies who promulgate disclosure to benefit a more authentic and integrated self and a more responsive and inclusive society (Bassler, 2009, 2014; Davis, 2005; Evans, 2017; Lingson, 2008; Mueller et al., 2020; Ragins, 2008; Shakespeare, 1996; Söderberg et al., 1999; Stone, 1995; Valeras, 2009, 2010).

4. CF (RD) and Sense of Self/Identity. Most co-researchers in focus group two, apart from Arianna, struggled with the dilemma of concealment versus disclosure in the realm of identity as they did not want to be defined by CF (RD), in particular the limited perceptions of others in terms of who they are and what they can and cannot do. This is a common struggle for many with a non-visible illness/disability and progressive and/or acquired non-visible illness/disability, who "do not

want to be put in a box" but accepted for who they are which is "as nuanced as anyone else" (95, 96, 97, 98, 99, 100). The idea of others having a nuanced account of their individual identities came up time and again especially when making observations and recommendations for CF (RD) counsellors/ psychotherapists, and CF (RD) doctors, nurses, and all allied health, to be elaborated upon in super-ordinate theme six. "Knowing that it's not the same for everybody although there's some commonality," "going in with a clean slate," and recognizing that "we're all persons first and we just happen to have CF" were high on their list of caregiver attributes (101, 102, 103, 104, 105). Interestingly, whilst Arianna discloses her CF readily to others as it has been an integral and positive part of her identity, she too resists being defined by her illness so long as people perceive it as limiting her abilities (106, 107, 108). For example, when she was told she could not be a firefighter, that she "was a liability" because of her physical limitations, she pleaded "Just let me do it. I'll prove it to you; I can do it. Let me do it" (109). Here she provides further examples of her refusal to accept CF as restrictive, and conversely "using it as empowerment:"

> Arianna: Like what is going on? I was into every activity. I did figure skating, gymnastics. I ran track, I did synchronized swimming. I did diving. I never saw it as an excuse to not do something I just did it and if I couldn't do it then I'm like whatever like I was in army cadets for five years and I got awards and awards and awards. I'm not trying to brag but I will brag if I can…. and we knew that transplant was a possibility down the road we knew I probably wouldn't make it to a certain age, but I didn't … live my life knowing that or feeling that I could die tomorrow …. I think when I was younger. I used it as empowerment. Because people said I couldn't. So, I did it and I did it better than they would (110, 111, 112, 113).

Finally, a robust discussion ensued regarding how some co-researchers had come to accept CF (RD) more readily than others. Whilst Charles surmises that "having other health challenges probably made [his illness] a little bit easier to accept" he agrees with others that one's upbringing plays a significant role in one's sense of self/identity in relation to CF (114, 115, 116, 117). Kyle shares how his parents supported him by putting him in activities to clear his lungs. This helped him to cope with the realities of CF when young:

> Kyle: My parents … they found that doing physio with percussor and stuff really didn't do too much, but really help with the physio … going running. As I ran a block. I was coughing up my lungs, clearing things out. So, they put me in lots of sports, and they also put me in clarinet lessons, breathing exercises (118).

5. CF (RD) Positive Aspects and Meaning and Purpose in Life. Whilst co-researchers struggled with CF (RD) in various aspects of their day to day lives, psychological well-being as well as being defined by their limitations, they also found it has helped them to focus on what matters, to find meaning and purpose in life. This statement by Charles best summarizes the sentiment of some co-researchers in this regard, "live life full" (119). Marie and Jake discuss the importance of contributing to society. Marie finds her treatments "exhausting," however she persists "to contribute to society, so it makes everything else possible" (120). CF (RD) has spurred Jake on "to be a good productive member of society." It also motivated him to "do all these things [he] wanted to do with [his] life" short of drugs which would make him ineligible for transplant:

> Jake: I wanted to key into something Marie said contribute to society. That's a lot of what I feel is that it's almost like at a very young age I realized how much it costs to keep me alive with all the pills and all that stuff …. So, it's partly something that drove me to be a good productive member of society … You want to become a productive member of

> society. But also throughout all my youth I was kind of told that I wouldn't live past the age of 25. So, I spent you … as soon as I turned 18 or 19 and I was able to drive it was like you know this could be my last month alive. That's what I started thinking so you just start doing all these [things] we want to do in life…You know the one thing I didn't do, though … that if ever I wanted a transplant someday I couldn't have I've never done drugs… I don't want to botch it up (121, 122, 123, 124).

Along these lines Arianna clarifies that using "CF as empowerment" had not only been about "proving everybody wrong" but also "experiencing as much as you could" (125, 126). She continues that her purpose in life has been about educating new parents with kids with CF and embellishes upon some earlier points:

> Arianna: So, I think now my purpose is to educate these parents who think that their kids are going to die when they are five … I'm just trying to make it so these kids now can actually go and enjoy their lives… I think that my thing now is don't be afraid of it. It's not the end of the world unless you want it to be (127, 128).

Finally, in terms of meaning and purpose in life CF has taught Marie to "not take anything for granted," "become more organized" and "prioritize what really matters:"

> Marie: To come back to the purpose in life, I would say that in my case CF taught me not to take anything for granted, especially not my health… with CF I had to become very organized to do everything I need to do in a day so I think something it's good for you know as a person but also as a professional and you know learning to prioritize and what really matters versus having no time for BS (Laughs) (129, 130, 131).

6. Observations and Recommendations: a) CF (RD) Counsellors/ Psychotherapists- Attitudes, Knowledge and Skills; and b) CF (RD) Doctors, Nurses, and all Allied Health. Focus

group two's sixth super-ordinate theme is divided into two subsets, with the former aimed at CF (RD) counsellors/ psychotherapists and the latter the rest of the CF (RD) interdisciplinary team. All findings have been incorporated into the Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

6.a Observations and Recommendations for CF (RD) Counsellors/ Psychotherapists- Attitude, Knowledge, and Skills. Having shared both their problematical and positive experiences with CF (RD), co -researchers in focus group two had a better understanding of what they would require of CF (RD) counsellors/psychotherapists, which shall be elaborated upon here. This super-ordinate theme and subset are further divided into the following areas as in focus group one: attitude, knowledge, and skills in accordance with Topic Guide questions five and six and the expressed needs of co-researchers.

Attitude. Co-researchers in focus group two spoke about non-judgment as well as other attributes on the part of a counsellor/psychotherapist as important for them to feel that they can "have that full trust in somebody," talk openly and engage in the process of therapy. Attitudes considered crucial include letting patients know "I'm here if you need me" without being too "nosy," "compassion," "empathy," being "down to earth" and "humour" (132, 133, 134). Arianna, Charles, and Jake speak to some of these points:

> Arianna: Hey, come on in. I need to talk to you about something I want to be able to have that full trust in somebody that I'm not gonna feel like an idiot and they're not going to look at me and go really that's your problem cause that's a huge deal (135).
>
> Charles: With my therapist … I know we have some laughs sometimes, so humour is always a greater experience making light of certain things, so we always have a few good

laughs. For sure, we're talking about some serious things for sure, and but I think humour is an important element and brings a better experience for me anyways (136).

Jake: My counsellor is very down to earth and forthcoming and easy to talk to and easy to listen to you. So that's a good trait to have in in anyone who's speaking about CF matters (137).

Knowledge. Counsellors/psychotherapists should have "excellent knowledge of CF," however, understand that, not everyone with CF (RD) is the same. They are "persons first" and may not want to focus on CF (RD) when they reach out for help (138). Charles and Marie summarize this well:

Charles: One of the things that I appreciate I think we've all touched on with counsellors is excellent knowledge of CF and knowing that it's not the same for everybody but knowing about the treatments and the conditions and the uncertainty with CF. Yeah, that's a recommendation. I would have to any therapist … Is being very knowledgeable on the CF condition itself (139).

Marie: It's very important for me that the counsellor knows what he or she is talking about when she's talking about CF. But I would also have that I think we're all persons first and we just happened to have CF, so I think there we are so many other things and it's important to remember that and there's so many other things going on in our live … Don't necessarily want to only focus on CF when I'm speaking with the counsellor (140).

Co-researchers also stress the importance of knowledge that is "beyond a textbook" understanding and based on real life experience with persons with CF (RD). For example, counsellors/psychotherapists should know what persons with CF (RD) go through inclusive of the experience of transplant, be aware of medications and possible long-term effects, understand the

progression of the illness and impart this knowledge, and be aware of relevant services (141, 142, 143, 144, 145, 146). Kyle summarizes the sentiment of the group as follows:

> So just knowing good routines as well as I guess stressors that come with CF which could be relationships or just only other people and being comfortable about it. That's using I guess oxygen tank in public. And knowing about like what the progression of CF will be as well as financials. It's important re lung transplant (147).

Finally, Arianna introduces a different perspective regarding the necessary knowledge of counsellors/psychotherapists, referencing her experience with a psychiatrist that had been beneficial because she was "outside CF clinic" and therefore not "focused mainly on CF" (148). It is worth noting that most counsellors/psychotherapists who work in the field of CF do not solely focus on the illness but rather start where the client is at because each person's identity and experiences are not limited to CF. Nonetheless this is a common idea and aligns with the notions of CF (RD) and sense of self/identity and not wanting to be singularly defined by the illness.

Skills. In terms of skills important to counsellors/psychotherapists when working with those with CF (RD) co-researchers in focus group two highlighted the importance of mindfulness exercises at the outset of sessions, teaching different techniques to cope, reminding one of past progress when "one falls back a few steps," pointing out patterns of behaviour and offering relevant resource information to learn and grow from each therapeutic experience (149, 150, 151, 152, 153, 154). Charles speaks to the benefits of "mindfulness exercises":

> I think just talking about knowledge and skills … I find it really helpful as well, and relatable for me in terms of my practices is mindfulness the mindfulness exercises that we do at the beginning, the grounding the really checking in with ourselves, clearing our minds, and I just said something that I find is a rarity in terms of some counsellors that

would've been in the past. So, I find that to be extremely useful … What a difference that makes (155).

Arianna brought in the idea of counsellors/psychotherapists utilising creative options for therapy instead of "old fashioned therapies or old-fashioned counselling." She explains this concept referencing her personal issues:

Yeah, I think to be creative. Like I think we all have a sense of … nobody wants old-fashioned therapies or old-fashioned counselling like tell me your problems and Oh well. We can't do anything well. Besides like besides talking and activities and stuff, I found journaling helps me a lot. And I think journaling would help other people quite a bit. But I think if we were to actively journal our issues and then actually send them to our counsellor can read them and then give us feedback on it as well. So, like say I'm having a really bad day today. I feel like the guilt is really overwhelming, and I can't deal with it today, so I write about it and then I send it to my therapist and … she says, OK, well, maybe the next time you feel this way when you write it down, maybe draw something or just to be more creative about how to deal with it rather than just sit there and say, OK, let's talk about it. Sometimes I don't want to talk about it maybe. Maybe I have to listen to music. Or read a book or write a poem or something else like a lot of us are very creative people (156).

6.b Observations and Recommendations for CF (RD) Doctors, Nurses, and Allied Health. Having discussed the attitudes, knowledge, and skills important to CF (RD) counsellors/psychotherapists co-researchers in focus group two turned their attention to observations and recommendations for their CF (RD) interdisciplinary team. The need for doctors to counsel them about the progression of CF so that they can anticipate and "prepare for the future" is articulated by Kyle:

> Response was it's different for everybody, which it is. I think there's some commonality too and sense that you'll go through life. You'll be able to do some exercise then after a while, not so much. … So just telling CF patients what the progression is going to be so they can keep an eye out … to help out and prepare for the future (157, 158).

Arianna brings in the idea of the team "going in with a clean slate" because not all persons with CF are the same. She also stresses the importance of a positive attitude because "CF people are the most positive people you will ever meet:"

> Some doctors will compare us to other patients and think that we're all the same. We're not all the same in any way, shape, or form. Jake could have different medications than I have in they affect him differently than they would affect me. Or I think going in with a clean slate to all your patients is the best have a background knowledge of what CF is and all the CF people that I've ever met are the most positive people you will ever meet in your life and I think they need to go in knowing that these people are positive. You come in with a frown on your face and if you're grumpy, Oh we'll let you know right. I'm not like this, you can't be like that (159, 160).

7. Counselling and Psychotherapy Experiences: a) Helpful Experiences. This super-ordinate theme aligns with Topic Guide question eight and, like super-ordinate theme six, informs the patient-centred framework (Appendix H). Three co-researchers in focus group two shared their helpful experiences whilst none relayed unhelpful experiences. I will therefore elaborate upon the former here.

7.a Counselling and Psychotherapy Experiences - Helpful Experiences. Charles shared his experience with mindfulness exercises at the outset of a counselling session both to emphasize important skills for a counsellor/psychotherapist and to highlight a helpful experience, in

alignment with his pre-existing practices (161). Jake and Marie share their beneficial experiences with therapists who have helped them respectively to move past feeling "freaked out" prior to transplant and "share the truth" unfettered. These experiences brought a sense of "reassurance" and relief. Importantly, both Jake and Marie brought in the idea of counselling/psychotherapy being helpful when one needs to reach out and talk to someone who is not family:

> Jake: I did when I was going for transplant go to a really good therapist … and basically it was because there was things, I was too nervous to talk to my wife about or I was basically a broken record talk, but I was just waiting for transplant, and I was freaked out. So, it was good to talk to her. She was a different change of pace. She had a more scientifical approach … she was just kind of explaining the reason why you're feeling this is because it's a feeling from your hypo dermis or something from your brain and so she gave me a lot of reassurance … about what my stress points were coming from (162).
>
> Marie: So, I haven't had a lot of experience talking to my therapist yet, but it was so amazing to just be able to tell the truth. And just say anything I wanted to her, and she just listened and wow. It was like woooh (motions relief) lot of yeah. So, I think that's very important to just having someone it's not because I have no one. It's because I don't want to tell them some things so having one person that you can talk to is amazing (163).

8. Feedback and Suggestions re: PAR Methodology: a) General Comments and Dissemination of Results; and b) Fostering a Sense of Community. Super-ordinate theme eight is divided into two subsets, based on the section of the Topic Guide: reflection questions on methodology used in the research. The first subset reflects answers to questions 10 through 12, whilst the second subset evolved from observing the sense of community that developed between co-researchers engaged in PAR. This researcher shall elaborate on both subsets here.

8.a Feedback and Suggestions re: PAR Methodology - General Comments and Dissemination of Results. General comments from co-researchers regarding PAR methodology include the benefit of the focus groups so that persons with CF can give meaningful feedback to one another versus doctors who have limited knowledge of their day-to-day experience (164). Regarding the latter point, here is an example of an exchange between Kyle and Charles:

> Kyle: I think people who have the disease are probably better to give feedback on what's going on versus doctors because they don't live with it every day. Then they don't know like don't take into account relationship issues and smaller aspects of it.
>
> Charles: Yeah … I think bang on is that you know we live with feel this every day right? So, our involvement is paramount I think in potentially helping others as well. So, I completely agree and I'll second that (165).

When the discussion turned to sharing the framework with other CF patients at the Ottawa clinic and requesting feedback from them before finalizing it, all agreed that this was a good idea for various reasons including the following: "we don't learn unless we share;" "it's a good idea… maybe people who are not available or who don't wanna participate in a group setting might have good … things to suggest;" and "Yeah, it's a larger pool of data … it would continue to improve things to the benefit of everybody" (166).

Regarding the dissemination of results Charles and Arianna had an initial exchange about "not liking the pamphlet idea because people just throw them out." This turned to not eliminating pamphlets "to get the information out as much ... and in as many ways as possible" (167, 168). Other ideas regarding the dissemination of results include having different options for counsellors/psychotherapists/medical professionals versus patients in terms of "getting the word out." As example, journal articles, technical/published papers and "CF forums and conferences"

for professionals versus short videos and creating a national registry for CF information sessions and group meetings for patients (169, 170, 171, 172). Arianna has this to say regarding the benefits of publishing a journal article which could create continuity of CF care in the realm of counselling across Canada:

> If it's a medical study and it's written out and its journaled … then maybe it'll get more kick back in other clinics in other areas like if they read it and say, Hey, well, if Ottawa is doing this, let's try it here and if it works like let's give our feedback … in that way, say I moved to, I don't know, Alberta if the Alberta clinic has adopted our counselling philosophy or our counselling study then I'm not going in blind and it'll be the same around all the CF clinics. And I can walk in there and say, Hey, I'm coming from here. This is what I'm dealing with. How are you guys set up? Oh well we're doing the same thing that you guys did. Perfect. I know how the system is going to work and hopefully it'll be general for everybody (173).

Finally, Kyle and Charles discuss having the patient-centred framework available on the CF Canada website to inform parents and those with CF "how to care and treat through some challenges that are faced with CF:"

> Kyle: Add to that even having that information available on CF Canada website. And then when you have a parent that comes in with a child cause they need to know all this stuff as well. Direct them there, so they are understanding what their child is or will be going through as well, and then maybe there's something that they will be going through too.
>
> Charles: Yah I find that some of that information can be pretty scary. I know it was scary for me in the beginning. I resisted to some of that this is an opportunity. That's more on the

positive side of you know how to care and treat through some challenges that are faced with CF (174).

8.b Feedback and Suggestions re: PAR Methodology -Fostering a Sense of Community. Many co-researchers commented about the benefits of PAR, in terms of fostering a sense of community. Being together in a focus group helped them to learn from one another and feel connected with like others with similar issues. Charles stated, "Just sharing of ideas… really onto something for sure" followed by Marie, "being able to ... speak together and talk about it can make a big difference" (175). The sentiment of co-researchers regarding PAR having fostered a sense of community is best summarized by Arianna who has been inspired by the process to reach out to others should the need arise:

> Everybody in this little group I love everybody because you guys are all fantastic and I love you. I would message anyone of you and say, hey, this is what's going on. What should I do? Because I just have that instinct and I know like if I message Kyle and say hey, this happened to me the other day has this ever happened to you? What do I do? (176).

Summary Reflection Focus Group Two. Findings for focus group two highlight the complexity of living with CF (RD) and the spectrum of experience of those who struggle with the illness. Some are diagnosed at a young age and others much later in life which has implications for how they view themselves and their place in the world. Living with a non-visible illness/disability in addition to the fluctuating nature of CF (RD) puts one at odds with a society that honours able bodies and forces one to either conceal or disclose one's illness. The dilemma of concealment versus disclosure adds to the burden of managing intimate relationships, treatments, and other aspects of the disease. The psychological impact may be experienced as not feeling good enough. Alternatively, having CF (RD) calls into focus one's meaning and purpose in life – "live

life full." Some with CF (RD) may feel helpless at times at the behest of not only the progressive nature of their illness but also the knowledge and disposition of those who treat them, members of their interdisciplinary team. Focus group two teaches us as counsellors/psychotherapists/interdisciplinary team members to understand and appreciate the nuance of living with CF (RD), and to treat everyone with respect meeting them where they are at as unique individuals. Even whilst sometimes covertly stuck at the storming stage of group development we again witness the need to come together as community, to connect with like others, made even more poignant by their compulsory isolation. PAR has provided the platform to do so. Through their efforts co-researchers in focus group two have furthered The Patient-Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis.

8.1.3 Focus Group Three

General Characteristics of Co-Researchers. Focus group three took place on October 8, 2020, at 6:30 pm. The focus group and preparatory meetings were held on MS Teams to circumvent cross contamination and infection from COVID 19. Like focus groups one and two COVID had considerably impacted the lives of co-researchers in focus group three and, as in focus group one, this became a topic of discussion. This will be further elaborated upon in the super-ordinate theme 1.g Experience living with CF day-to-day- CF and the impact of COVID, in the detailed analysis of the super-ordinate themes which follows.

All co-researchers in focus group three at the time of this study fell between the ages of 24-30. They face all the developmental hurdles of others in their age range, for example, individuating from family, choosing careers, and finding partners, however, as one co-researcher stated, their normal is "not the normal day to day." Managing debilitating symptoms and arduous

treatments amongst other factors has made navigating life's challenges substantially more difficult. It is important to recognize that because of their age, co-researchers in focus group three would have had access to protein modulators that were not available to the older group. Whilst still being told that they had a shorter life expectancy, their quality of life may have been positively impacted by the advent of these new medications. Still, CF is a spectrum and co-researchers have been disparately impacted by the illness. This will be expounded upon in super-ordinate theme 1.e Experience living with CF day-to-day- CF as spectrum.

Focus group three is made up of seven co-researchers, Jill, Karen, Kallie, Khris, Charlene, Jay, and Michael. For the purposes of confidentiality all names, except for that of our research assistant and this researcher, are pseudonyms and have been agreed upon by co-researchers. Charlene and Kallie co-facilitated focus group three with our research assistant Rebecca as backup should either one choose to opt out for any reason and to act as time keeper.

Co-researchers in focus group three in the icebreaker exercise introduced themselves as follows. Kallie "started everyone off" by expressing her "excitement to be here." She shared that she has been "taking advantage of this weird COVID time to take a lot of time to hike and to learn how to golf for the first time this year." Charlene shared that she works in mental health and that she was "supposed to get married this year, but that got delayed." Otherwise, a "little fun fact is that [she] plays violin." Jay is new to the Ottawa area and an electrician by trade. Khris expressed that she has CF and is "working on going back to school." She is "hoping to write children's books about CF or any sort of underlying health issue." Jill works in IT and "has been home since the very first case in Ottawa in March …holed up in a one-bedroom apartment." Michael is "Franco Ontarian and bilingual. [He] has been at the Ottawa CF clinic since [he] moved to the region in

2009." Karen works for the government part time and has been at the Ottawa CF clinic for six years. She "used to be followed at the CF clinic in Toronto."

Socio-Demographic Details. Please see Table 3 below for a visual representation of focus group three socio-demographic details, followed by a written summary:

Table 3

Focus Group Three Socio-Demographic Details

Name:	**Jill**	**Karen**	**Kallie**	**Khris**	**Charlene**	**Jay**	**Michael**
Age:	24	25	27	29	30	30	30
Gender Identity:	Female	Female	Female	Female	Female	Male	Male
Age at CF diagnosis:	Birth	18 months	4	2	6 months	9 months	3 months
Language:	English	English/ French	English	English	English/ French	English/ French	English/ French
Living status:	Living with partner	Living with parents	Living with partner	Living with partner	Living with spouse	Living with spouse	Living with partner
Relationship status:	Partnered	Single	Partnered	Partnered	Married	Married	Partnered
Employment status:	Full-time	Part-time	Full-time	ODSP	Part-time	Full-time	Full-time
Education:	College Diploma	University: undergraduate	University: undergraduate	High School	University: graduate	High School	College Diploma
Are you a person with (CF18-30; CFRD; CF39 +; Other):	CF 18-30	CF 18-30	CF 18-30	CF 18-30	CF 18-30	CF 18-30	CF 18-30
Do you identify as a person with Non-visible illness/disability?	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Previous Counselling and Psychotherapy experience?	No	Yes	Yes	Yes	Yes	Yes	Yes

There existed only a six-year age difference amongst co-researchers in focus group three. In terms of the gender identity of co-researchers, fully five identified as female and two as male. Age of CF diagnosis for all but one co-researcher fell in the early diagnosis range with Kallie being diagnosed at four. This is a more typical profile in terms of age of diagnosis with most persons with CF diagnosed from infancy to two years of age. Four co-researchers identified as bilingual English/French with three identifying as unilingual English. Co-researchers mostly resided in the greater Ottawa area. Living statuses included six co-researchers living with their spouse or partner and one co-researcher living with their parents. Four co-researchers identified their relationship status as partnered, two as married and one as single. Four of the co-researchers cited their employment status as working full-time, two as part-time with one supported by ODSP. Five out of seven co-researchers had either a college diploma or university degree, one at the graduate level. Two co-researchers had completed high school. In terms of identifying with one of the three groups in this study - CF aged 18-29, CFRD, CF aged 39 + - all marked CF 18-30, in this respect a homogenous group. All seven co-researchers marked yes to identifying as someone with a non-visible illness/disability, with some elaborating as follows:

Jill: “CF and Scoliosis.”

Karen: “It’s a medical condition that another person would not be able to determine by just looking at you. My disease manifests internally primarily, therefore I don’t require physical aids.”

Kallie: “Illness yes but disability no.”

Khris: “I have an illness no one can see unless I point it out.”

Charlene: Considering the amount of time needed for medical treatments on a daily basis, as well as the frequent absences due to exacerbations or hospitalizations, I consider it a disability as I have required medical accommodations as a result. I also think that our constant coughing and need for treatments or adjustments to our routine does have an impact on our living in society and is an additional obstacle to living and functioning normally.

Jay: “Physical activities, beyond walking incur shortness of breath and in some cases exhaustion, thus making work life in particular rather difficult.”

Michael: “I have cystic fibrosis which is a disability, but I don’t let it stop me from doing whatever I want. Also, it’s not apparent on the physical side.”

Finally, all but one co-researcher in focus group three, Jill, marked yes to having had previous experience as a client/patient in counselling and psychotherapy. The following are co-researchers’ response elaborations:

Karen: “I started therapy after having gone through an emergency neurosurgery. Through the process I was diagnosed with ADHD. I now take medication and am thriving!”

Kallie: “Yes I was once recommended to a private counsellor through the clinic. I had about three-four sessions with her, but we were not a good patient-counsellor ‘match.’”

Khris: “Since childhood on and off.”

Charlene: I have used counselling services twice in the past. Both instances were short-term services. First time was for panic attacks unrelated to my health. The second time was related to coping with challenges and systemic issues in getting support throughout illness, including disability insurance, financial support, and access to medication. What I found

helpful was to identify and understand better the various resources and supports that could be used alternatively if insurance and medication access were restricted, but also exploring my fears behind it, in order to be better prepared.

Jay: I have been seen by a psychologist a few times, typically in regards to CF. Had the unfortunate experience of receiving generalized anxiety disorder and the subsequent psychiatrist appointed to me was not concerned about my health so much as creating a drug induced stupor.

Michael: "I have follow up with a social worker."

PHQ-9 Scores. All co-researchers in focus group three scored in the none-minimal (zero-four) to mild (five-nine) range on the PHQ-9, with the highest score being nine and the lowest one. Regarding the degree to which their problems "made it [difficult] to do work, take care of things at home, or get along with other people," two co-researchers marked "not difficult at all," four marked "somewhat difficult" and one marked "very difficult." It is worth noting that all had an affirmative answer to somatic question four, "Feeling tired and having little energy," and all but one co-researcher responded affirmatively to question six, "Feeling bad about yourself -or that you are a failure or have let yourself or your family down." This may speak to their perception of their illness (Umwelt) on the self (Eigenwelt) and their relationships (Mitwelt). No co-researchers answered affirmatively to question nine, "Thoughts that you would be better off dead or hurting yourself in some way." Due to the low scores of co-researchers in focus group three on the PHQ-9 and the lack of affirmative answers to question nine no further intervention had been warranted on the part of this researcher.

GAD-7 Scores. GAD-7 scores for co-researchers in focus group three were lower than that of the PHQ-9 for all but one. All co-researchers scored in the none-minimal (zero-four) to mild

(five-nine) range, with the highest score being seven and the lowest score being two. In terms of the impact of their problems, the degree of difficulty, in the various life domains, two marked "not difficult at all" and five marked "somewhat difficult."

Group Dynamics. There were two notable group dynamics in focus group three: 1) the sense of community that developed amongst co-researchers, which this researcher will elaborate upon in super-ordinate theme 8.b. Feedback and suggestions re: PAR methodology -fostering a sense of community; and 2) the seamlessness with which group three moved through the five stages of group development - forming (familiarizing), storming (the group encounters difficulties), norming (developing cohesion), performing (accomplishing tasks) and adjourning (closure) (Owen, 2001; Tuckman & Jensen, 2010). As one group member noted, "there were few differences of opinion and only vibing off one another like our lives depended on it." Many had not had the opportunity to converse with others so intimately with CF and the experience of being in the focus group left them feeling "enriched." The following brief remarks by co-researchers exemplify the "give-and-take atmosphere" and "mutual aid feeling" of the group:

Charlene: "Really good point, I agree."

Jay: "Yah I'll pitch in my two cents."

Karen: "I really like what you said Jay about that idea of movement."

Kallie: "That's a really good recommendation. Thanks for sharing…. One thing that I really related on is…"

Khris: "I wish there was like a hell yes button (Karen laughs)."

Summary Statement. Given the supportive dynamic amongst co-researchers in focus group three it is not surprising that it lasted for three hours, far longer than any other group, with some "reluctantly leaving" at the end because they "had to do treatments" or had "run out of

steam." The feedback from co-researchers after group was very positive, including the debrief with the co-facilitators. For example, one co-facilitator commented on the "supportive environment" which "felt empowering" leading to "a wakeup call." The other co-facilitator had the following to say, "normally if people with CF meet it could devolve into negativity but because this had a purpose, [the framework], the conversation was always constructive." Based on these comments and others it is likely that co-researchers experienced a common humanity, a sense of community in developing a framework for counselling and psychotherapy in alignment with their values and needs. Again, Nouwens' words are prescient here:

> Community is a place where we are constantly called to lift up each other's gifts. Not each other's unique talents, but precisely these gifts of friendship, of peace, of joy, of pain, of sorrow that we have experienced together. Sometimes that becomes more visible through involvement with each other (Nouwen, 1992, as cited in Lazarus, 2021, p. 106).

Super-ordinate Themes. The following is an analysis of the eight super-ordinate themes and subsets (below) for focus group three. Relevant quotes will be highlighted along with the corresponding emergent themes to capture the depth of the experience of co-researchers. A summary reflection will follow:

- 1. Experience living with CF day-to-day: a) symptoms and treatments; b) interpersonal relationships; e) CF as spectrum; f) CF can be a dark disease; and g) CF and the impact of COVID;
- 2. Psychological Impact of CF: a) interrelationship of physical and mental health; and b) isolation from others with CF;
- 3. CF as a non-visible illness/disability: c) the ignorance of people;
- 4. CF and sense of self/identity;

- 5. CF positive aspects and meaning and purpose in life;
- 6. Observations and recommendations: a) CF counsellors/ psychotherapists-attitudes, knowledge and skills; b) CF doctors, nurses, and all allied health; and c) the healthcare system;
- 7. Counselling and psychotherapy experiences: a) helpful experiences; and b) unhelpful experiences;
- 8. Feedback and suggestions re: PAR methodology: a) general comments and dissemination of results; and b) fostering a sense of community.

Experience Living with CF Day-to-Day. Focus group three co-researchers centred their discussions on living with CF day to day on five themes or subsets: a) symptoms and treatments; b) interpersonal relationships; e) CF as spectrum; f) CF can be a dark disease; and g) CF and the impact of COVID, which this researcher shall elaborate upon here:

1.a Experience Living with CF Day-to-Day - Symptoms and Treatments. Co-researchers in focus group three spoke about the deterioration that one experiences as one ages with CF and being different from "normal folk" in terms of how they feel in their bodies and their arduous treatment regime. They then turned to their emotional struggles regarding their treatments, for example, finding the motivation and allowing oneself to not be perfect "every single day." One co-researcher, Michael, shares in a self-deprecating manner, that he is "full of shit" because he doesn't always adhere to his treatments even though he knows that he should. This we will see in part has to do with his relationship with CF. Finally, co-researchers have a nice exchange at the end of the focus group, where they discuss having to leave because it's "bedtime treatment time." The latter offers a window into not only their treatments but also their shared bond and sense of

humour. Khris begins the conversation by sharing how she now experiences CF, and in doing so employs an interesting analogy:

> So, I would say the day to day it it's getting a bit difficult, especially with age. I find. It's like a car, you know, after that, that like warranty. The car starts to kind of deteriorate a bit, and sometimes I feel I'm too healthy to be in the sick life, and too sick to be in the healthy life, so I hope I answered that properly (laughs) (1).

She is followed by Jay, Khris and Charlene who variously describe how their lives are "not the normal day to day" but in fact a "constant struggle" and "very time-consuming:"

> Jay: Uh, also the understanding that our normal isn't normal. Um I mean what I consider normal day to day. I don't know anything else. I don't know what it is not to do these things for me because like it's just so built in …. everything that stems from like taking pills for everything, the amount of meds you take…. I mean, as a kid I couldn't understand that other people didn't take pills when they ate … to me, I didn't understand. So yeah, that's like your normal isn't the same. As what other people's quote normal would be (2).
>
> Khris: I have a feeding tube so I've gotta clean that. I've gotta clean you know the bag, the gravity bag. I have to clean the nebulizers… time management is huge and you know Jill would say she has to be in bed by 9. I mean we all have to. It's crazy how much more time consuming our life is compared to the I'm going to talk about normal folk (3).
>
> Charlene: But I mean obviously like for me, there's like the day-to-day routine, with the medications and trying not to forget anything…. continually having to struggle of like oh, if I forgot this medication then like have to remember to take it later …. But then I forget something else. You know that constant struggle of having to stay on top of things…. And obviously like it's very time consuming, so that's one thing that I notice on my day to day

> … it takes up so much of your time, but not just like the medications and the hospitalizations, but even the routine appointments like having to go to the pharmacy like doing all of those coordination is just so time consuming in your schedule (4, 5).

Jill and Kallie speak to one of the "main problems with CF" which is "motivation for treatments," with Kallie resolving to "do the best you can do that day … even if it's not exactly what the doctor has prescribed" (6, 7, 8). Along similar lines, Michael describes struggling with treatment adherence and disparages himself for not taking better care the way that he should:

> It's probably because since the beginning I called myself … a full of shit kind of person cause I haven't been really good at taking care of myself, but I'm still at 30 years old that I'm actually training for a triathlon right now. So, I'm kind of being full of shit. So, I've been doing some follow ups with my therapist and when she told me about this, I'm like I want to go in cause I'll probably like the whole of reverse of everybody cause I am pretty bad at this (9).

Finally, Jill, Khris and Karen have a sequence of exchanges at the end of group bemoaning having to leave because they must attend to their respective treatments. The exchange offers a rare insight into their nighttime routines and their shared humour speaks to the bond they have developed over the course of group where they have felt "safe:"

> Jill: Uh, no, I think it was all pretty covered so far. It's just that I do work early tomorrow, so I was wondering if I may also like dip early cause I just have to. You guys know I gotta do all the treatments in the morning and everything.
>
> Khris: We're going into like bedtime treatment time. That's why.
>
> Karen: This is the reality of living with CF.

Khris: We don't want to get off the phone we have to…. Yeah, I don't know if you guys saw it I was taking some meds during our call while eating meds. I saw Charlene eat I'm like hey I'm safe.

Jill: Yeah, I'm gonna go grab my Orkambi and have like some popcorn for some fat or whatever Oh my God.

Khris: Right yeah have you tried the dill pickle shake?

Jill: No, I haven't.

Khris: There's salt in it.

Jill: There are certain lines I will not cross.

Khris: I add butter and then the Dill Pickle dip.

Jill: Oh, my goodness, you are braver than I Khris (laughs).

1.b Experience Living with CF Day-to-Day- Interpersonal Relationships. Discussions amongst co-researchers in focus group three regarding their interpersonal relationships moved from the more general, for example, having to deal with people on a social level, to the specific, for example, fertility and intimacy. Here, Jill speaks to people's "preconceived notions" of CF which fall short of reality and can have an impact on self-perception of one's physical appearance:

Jill: But I guess like pre-pandemic problems living CF and I'm sure some of you can probably relate is that you know just a lot of people don't understand just how all-encompassing it can be and a lot of people also have preconceived notions of what it is from, you know, the few examples like you know, there's always the token CF episode in Grey's Anatomy or the token CF patient or the movie 65 Roses. So especially now that we're more in the media. Which is great for you know. Teaching people a little bit, they now get those preconceived notions of what it is. So, like for me, personally when I was

> younger, I never had a problem gaining weight, so people would like Oh yeah I have CF. Oh really, I never would have guessed I thought everyone was just so skinny. And it's like, OK, thank you. So, I think just dealing with that perception that some people have in their heads. That's definitely something that comes up living with CF (10, 11).

Charlene also talks about people's misperceptions about CF, for example, "on a social level when people see [her] cough," and she has chosen to be "transparent' and to "educate" them as part of her day to day (12). CF in closer relationships may be a little more difficult to navigate, however. Jay speaks to "being strong for the people around you" lest they "freak out." Karen has had to cancel on friends which was misinterpreted as her "not wanting to bother." In both instances, Jay and Karen conceal their true state of health which comes at a personal cost:

> Jay: Uh, because it's easy to default to. I have to be strong for the people around me or else you're going to freak out. So, no I got this covered. It's fine, but really I'm dying inside and I gotta like up down my eyeballs in problems (13).
>
> Karen: … especially going into University, I was working and then I was going to school, but I was exhausted so I said no to a lot of social events last minute and people were and I got a lot of messages of like, Oh, you just don't want to bother and I didn't feel comfortable saying hey, actually. When I went home, I like crashed on my couch (14).

Karen has learned from her earlier experiences with friends and now is more transparent about her limitations. CF has "allowed for vulnerable conversations" and "finding community in that:"

> And but also, it's opened up conversations with friends where I'm like. It may very well happen that three hours before we're supposed to meet, I'm going to cancel on you… and it's allowed for very vulnerable conversations with friends to be like our pain may be different, but the experience of it we can find community in that (15, 16).

Family may be impacted adversely by CF, and it may feel futile to reach out for support as they are "dealing with their own issues" on how to cope with one's illness. Khris shares her experience with family which results in concealing her emotional pain:

> I'm not going to say I broke up my parent's relationship cause I know that's not the case, but I'm sure that it was definitely difficult. You know there were a lot of times where my dad was so strict when it came to treatment and my mother was like I feel like I'm punishing healthy, you know? So, they weren't on the same page…My family is unable to help and guide me because they're dealing with their own issues on how to deal with me being sick… I kind of block them out a lot as to what is actually happening with my body … when I'm in hospital I do the same thing. My sisters are there. They're crying. They're losing their shit and I'm like it's okay guys, I'm fine. When everyone leaves, I cry myself to sleep at night. It's just part of it, you know (17, 18, 19, 20).

Finally, in terms of intimate relationships, CF means "being apprehensive about dating," or, alternatively, having to "step out of your comfort zone to have difficult conversations" about your body, infertility, sexual intimacy and "preparing your partner to bury you" (21, 22, 23, 24, 25, 26). One co-researcher brought in the notion of being her "fiercest advocate," which has the negative effect of shutting people out, "when you get into that kind of mentality it's very hard to let people in" (27). Kallie speaks to finally finding a supportive partner after having dealt with the insensitivity of some men:

> I think maybe not to the same extent, but I've also started kind of noticing changes in my body that way and it's great when you have a supportive partner, such as I do now, who again is very understanding and open and listens, and if you have the gross stuff, they're just like it doesn't matter. Like, will blow his nose and be like look, I got gross stuff too,

> but I've also dealt with shitty people in the past which maybe speaks more to my interesting shitty men. I've had somebody say to me like, well, why would I pursue a future with you if you have such a low life expectancy? (28).

1.e Experience Living with CF Day-to-Day- CF as Spectrum. When discussing CF as spectrum co-researchers in focus group three share how it impacts "each person differently" and the fluctuating nature of the illness which requires considerable practical and psychological adjustment. Apart from waking up each day to a different illness presentation and having to "balance" one's day to day life with this "new normal," CF is a progressive illness and co-researchers must also adapt to their "evolving situation" particularly as they age. Karen and Jay emphasize the importance of understanding "CF as spectrum" and the reality that "where you are on the spectrum changes day to day." This is followed by Michael and Jay who describe how CF shows up differently in their bodies:

> Karen: Having like spectrum of views, I'm like that I find is really key cause when people talk about CF they forget about the spectrum of how CF manifests for different people. And I'm like that's super-duper key (29).
>
> Jay: There's a spectrum and sometimes where you are on the spectrum changes day to day. So, it's not like it's a constant thing and there's ups and downs and you go sideways and sometimes hard to keep track of where you are (30).
>
> Michael: So, like me, my lungs are like pretty really good, but I'm five foot so me with all my digestive problems. I just couldn't grow when I'm when I was a kid. So, the only physical thing about me is that if I shave, I go from 30 to 17 years old. But other than that, everything else is normal (31).

> Jay: That's the whole issue, especially if we're for some of us have more of a breathing impairment. Um gastral intestinal issues GI stomach. That's always a CF favourite. I find it doesn't affect everybody the same way than others, but I mean me if I don't have my meds, If I don't have my enzymes like forget eating, it's not worth it (32).

Khris, Jay and Charlene talk about the effects of CF on their aging bodies, which impacts intimacy, requires help from one's partner, managing expectations, and a struggle to balance how much one can and cannot do. Khris begins by expounding upon her previous comments about "feeling like a car past its warranty:"

> I've gotten older with CF; I have more female issues and I'm sure this is for the guys too just a lot of things that I didn't expect to have in my late 20s happen in my body. So, I have to say that might be the hardest part. Uh, you know being 29 years old but having issues that happened to my body that shouldn't be happening till I'm in my late 50s. So, coughing and urinating or you know my partner has been helping me to set up my own meds. Sometimes we get up in the night because I've had an accident or something, so we've had to switch the sheets. So, I think living day to day with it it's gotten easier yet harder if that makes sense. You know, it's like a 50/50 deal. I mean, intimacy is definitely difficult when I'm on heavy medications. I used to make a joke that I would just do the starfish and kind of lay there, you know, so I mean, that's definitely comes into play as as I get older and I have a partner (33).
>
> Jay: The day to day for me now is a lot about managing expectations and making sure I don't bite off more than I could chew. My lungs have taken a big plummet for the last couple of years … So, there's a lot of that for now...The day-to-day stuff, which is different, and it's an evolving situation… these things change overtime, and you have to constantly

> evaluate. OK, how am I doing today? Is this a good day, is it a bad day? Should I be doing this? I have to do this thing later. You know, just time management of your effort and your energy is very different (34, 35).
>
> Charlene: And the last thing is also the struggle to balance. You know how much you're able to do versus how much you're not able to do cause obviously our health, like you know, fluctuates. And you know even same for me, like I've taken kind of a dive the last couple of years. And you know, kind of adjusting to the new normal. But at the same time I feel like sometimes I use it as an excuse so I feel like almost like I'm lazy to like not do something, but then when I do it then I realized that it was too much for me and then so it's just kind of like that balance of figuring out how much I should be doing with my health and not abusing of that either (36).

Finally, Jill and Karen discuss struggling with their declining health, pushing oneself to do something might work as does considering "mucus puking a win." This speaks to their tenacity, and the decision not to give in to despair. It recalls Frankl's concepts of freedom of will and humour and detachment. In the first instance, both Jill and Karen are choosing to persevere in the face of hardship. In the second instance, Karen employs humour to detach from her suffering diminishing its power (Block & West, 2013; Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Nochi, 1998):

> Jill: When I was younger you know it was up there and then like my PFTs [pulmonary function tests] were high and everything. And then I went down to a certain level like I've been there for the past so and so years and … you almost get sometimes until like that rhythm of just like if you don't do anything, it'll just stay the way it is. You know that

obviously doesn't work, so that's something that you know I do struggle with on a daily basis (37).

Karen: I know what it's like sometimes to wake up and be like today is really crappy and I would much rather be sun tanning in Cabo. But today I'm going to be mucus puking and in my PJs all day and that's going to I'm going to count that as a win (38).

1.f Experience Living with CF Day-to-Day- CF can be a Dark Disease. The theme of CF as a dark disease was repeated throughout focus group three and particularly in relation to living with CF day to day, the psychological impact of CF, CF and sense of self/identity, CF and meaning and purpose in life, and observations and recommendations for CF counsellors/ psychotherapists. The use of metaphor is often employed to make sense of difficult human experiences, and to describe and regulate severe emotional reactions to existential issues such as disease, death and meaning of life (Deng et al., 2021). Metaphors "can cast light on why we understand ourselves as we do" (Potter & Wetherell, 1987, p. 108). The words of co – researchers regarding CF as a dark disease are poignant because they are trying to make sense of their illness experience and themselves. Here, Khris, Jill and Karen variously refer to being "super sick and going into this dark hole," CF as "a dark disease," and "dark humour when you have our condition:"

Khris: I don't know about you guys, but when I'm super sick I go into this dark hole, where I'm like that's it. I'm done. I'm done with the meds. I'm done with giving a shit. I'm done. I'm over it. I've asked my mother, so many times. Please let me die. Please let me die. You know, and I need a counselor who's gonna be like sorry Khris you're living you're staying, and you better buckle up…. You know and I think a therapist needs to come in. Witty, dark humour we're all very dark. Let's be honest our humour. Listen, I don't know about you guys every time I go for a scope I write on my butt cheek. That's how dark I am (39, 40).

> Jill: I mean we are a dark disease and sometimes there's going to be times where we're going to be in a dark place so letting you know it's not a personal attack on them. Just recognizing that it is what it is. (41).
>
> Karen: You get a little bit of dark humour when you have our condition and I find sometimes I've made jokes and people were like Oh my gosh, I'm so sorry and I'm like no, no no I was kidding (42).

1.g Experience Living with CF Day-to-Day- CF and the Impact of COVID. Co-researchers in focus group three centred their discussion of CF and the impact of COVID on the following topics: people mistaking CF for COVID; people "not getting the serious impact of COVID on CF;" having to increase precautions because of their vulnerability; and the impact of COVID for mental health, treatments, and one's ability to adapt. To begin, Khris and Karen seem incredulous about "regular people" having a difficult time coping with COVID. Again, there is some "dark humour" here, "welcome to the dark side" (43):

> Khris: It's crazy all these people are like Oh my chest oh I'm sick. Oh quarantine. I'm like. Were sick, that's what we do. Welcome to the dark side.
>
> Karen: And like the whole, I wore a mask for two minutes and I just I just couldn't handle it. I was like, well, welcome to…
>
> Khris: I can't breathe.
>
> Karen: I'm like welcome to waiting in a waiting room for four hours with the mask on like join the club.
>
> Khris: Yeah.

The problem of people conflating CF with COVID at this early stage of the pandemic had become part of Karen, Charlene, and Kallie's day to day life. Karen and Kallie talk about feeling like they

have to justify their coughing whereas Charlene sees this as an opportunity to raise awareness about CF:

> Karen: If I'm coughing. It's like people give me such a weird look I promise I will not give you COVID. I promise this is just my day-to-day life (44).
>
> Kallie: And even just hearing about kind of people talking about their experiences with COVID and in in my head there's like a twisted thing where I don't want to make other people feel uncomfortable because I have a condition, so if I'm in a group of like a socially distanced three- or four-person group of people, my priority isn't like will they get me sick. But it's more. What will they think of me if I cough? I feel the need to justify to people Oh, I cough like I won't get you sick. I don't have COVID I don't ... it's a lung condition (45).
>
> Charlene: Yeah, I think that's probably going to be a reality for the next little while that, like people are going to be hypersensitive about people being sick around them or coughing around them. That it's something that's constantly going to happen because every new person that you meet on the street might not necessarily know anything about CF or might assume that you have COVID when you don't. So, I think that's just kind of like part of what I've come to expect out of social interactions. But I'm OK with it too, because it also kind of raises awareness for this (46, 47).

Others recounted insensitivity and "a mixed response" from friends and family in terms of understanding the increased risk to them of COVID, with only one co-researcher, Karen, describing a supportive supervisor who ensured much needed accommodations (48, 49, 50, 51). Karen summarizes the juxtaposition of her situation to that of her friends regarding COVID, necessitating "tough conversations:"

> Karen: Are you going into … pubs and then the first couple times that we talk about this they're like, are you worried that we'll infect you? And I was like, well, we've seen that the virus can be asymptomatic…You can put me at risk and it was a tough conversation at the beginning. … Then I wasn't able to get some of my meds for a little bit so I was on my last like the bottom of my like my med bin in my med cart and I was right at the bottom of it and I'm like I'm struggling to just have the pharmacy call me back for meds and you're talking about how you're so frustrated that your brunch plans were interrupted? And so then that was kind of a thing too where I'm like all right now with friends where it's like we're going to talk about this (52, 53).

The conversation turned to extra steps that are necessary to protect oneself from COVID and having to "balance the scales" by asking oneself "is this worth it?" before leaving the house. (54, 55). Some co-researchers found themselves isolated during COVID for various reasons, including having to work from home, which had a negative impact on their mental health and treatment motivation. For example, Michael reflected upon feeling "kind of depressed and lonely and stupid" and Jill stated, "I'm a people person and now I sit at home …it's been really hard to find the motivation for treatments … and you're like, well, what's the point of anything anymore?" (56, 57, 58).

Finally, Kallie and Charlene found some positive aspects to COVID, much needed time to do treatments and the realization that one can adapt due to living with CF:

> Kallie: I've gotten a lot better surprisingly during COVID, just because we're all sitting at home and you kind of have that time. And you can do your treatment while typing at a monitor. I find I can, surprisingly, COVID has been helping (59).

> Charlene: Yeah, I think for me, one of the biggest impacts and positive impacts of living with CF was the ability to adapt. So, for example, like I don't think that I would have been able to cope with COVID If I hadn't been used to already, like stopping my life for hospitalizations or having to like do, you know, change plans last minute and things like that (60).

2. Psychological Impact of CF. The super-ordinate theme psychological impact of CF for focus group three is divided into two subsets: a) interrelationship of physical and mental health; and b) isolation from others with CF, elaborated upon here:

2.a Psychological Impact of CF - Interrelationship of Physical and Mental Health. Co-researchers in focus group three talk about the unique "mental load" that they bear because, with CF, their mental health and physical health are intimately connected. For example, they must decide whether to take risks, push themselves and curtail treatments, knowing full well that this will likely have implications for their physical well-being and mental health (61, 62, 63, 64). A "mental load" in relation to CF may also mean having to cope mentally with "survivor looks" because one has "racked up a lot of health events" and is viewed as "the grandchild who's almost dying all the time" (65). One's mood may also "rise and fall" based on the results of one's lung function test or one's debilitating symptoms, "You know I'm gonna be super happy and up here because I blew a 58 and sometimes I'll be down here cause I haven't pooped in three days and I'm starving" (66). Constant hospitalizations may result in worry, "always being nervous that I don't know if I'll leave through the front door or the morgue" (67). Having CF may mean "feeling less of a person," and "being afraid to start a future" because it may all be "taken away" which can result in depression. These statements are related to existential concerns: the I-am experience, anxiety about the future, and uncertainty. Khris speaks to these points:

> So personally, CF it does make me feel like I'm less of a person. I'm always fearful that I'll start life and that CF will come right behind me and be like nope all that future you had planned, and I think that's my biggest struggle as I'm so afraid to start a future because I don't want it to be taken away from me. I don't want to have a beautiful life and a beautiful home and that be taken away from me, you know, as selfish as that sounds, I struggle a lot with the What ifs you know? I try to turn off those thoughts and those feelings … no matter how much medication I take, my depression will always be there just like no matter how many treatments I do, my CF will always be there and I feel I'm in this box and I don't know where I fit in life (68, 69).

Some have resolved to "keep moving," go into "survivor mode" or push through "when [their] bodies break down," however, this "can be very numbing emotionally" (70, 71, 72). Some "put on a default public face" or "convince themselves that they're fine … telling themselves I don't have time to focus on my emotional mind right now. I need to focus on the C Difficile or the pseudomonas that's growing" (73, 74). Still others "bury" their trauma as a result of having CF and now have the insight that "mental health in CF really do go together:"

> Khris: The first time I ever saw someone die from CF I was eight years old. So, from a very young age I was in and out of CHEO watching children die and, I was like, oh, that's just Four West that's what happens, you know, and now as I look back, I go I kinda have PTSD from watching kids die. I kind of have trauma. From seeing kids. You know a priest would come into the room and these kids didn't know, right? We didn't know a priest was there. Like oh OK, whatever. All we wanted to do was go outside and play and be off the IV… and I feel like there's a lot of people who bury that, and they go no mentally I'm fine.

> I'm super good. Oh, I have to get a second double lung transplant, but I'm super OK with it. No, you're not. No, you're not… Mental health in CF really do go together (75).

2.b Psychological Impact of CF- Isolation from Others with CF. Most co-researchers in focus group three talked about their social isolation from others with CF either in the icebreaker exercise or at the end of group or both, indicating their excitement to be with one another. The bond that developed as a result of being part of a PAR focus group will be elaborated upon in super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community. Michael shares that "one of the reasons [he] wants to do this …is because [he's] never met anybody else that has CF cause we're so segregated. So, this whole talk with people is pretty nice for me" (76). At the end of group he adds, "it was actually awesome seeing some people. I have not met one person since I've been in Ottawa with CF other than a couple people during the walk with CF in May" (77). Kallie too references isolation from others with CF at the beginning and end of group. She states at the outset, "this is my first interaction ever with people with CF, so it's pretty cool and looking forward to being part of this" and at the conclusion, "it's really great to kind of touch base with other people because we don't have a chance to do this" (78). Khris also discloses that she has been isolated from others with CF sharing in her introduction, "I'm very new to this as well" (79). Finally, Khris and Jill share that, although attending the same high school, they were "searching for each other" without success. Perhaps because of confidentiality and the risk of infection no adult assisted them to find one another (80). It is almost inconceivable that those with CF must navigate the devastating implications of their illness in isolation. Social isolation in those with CF has been associated with reduced physical and mental health, quality of life and clinical outcomes (Gulledge et al., 2021).

3.c CF as a Non-Visible Illness/Disability- the Ignorance of People. CF as a non-visible illness/disability generated a lot of discussion between co-researchers in focus group three. The subset, "the ignorance of people" was originated by Khris and this theme runs throughout the entire discourse. Co-researchers share experiences where they felt misunderstood, disbelieved, and judged necessitating conversations and self-advocacy even when physically ill. Feelings of being misunderstood at work may cause one to feel "aggression" or, alternatively, shame. Even when well meaning, people may assume "what you need" and must be taught that there is "a middle ground," which requires guidance. Some "treasure" having a non-visible illness/disability versus a visible illness/disability because "it's really hard to get away from assumptions" if you're the latter. Some have chosen "to be open about" their CF but even then, one co-researcher shares an early childhood experience with a teacher that was "mortifying." Finally, CF is primarily non-visible but may be visible and when it is people may stare or "whip their heads." Perhaps the best thing to do in this instance is assume one's CF body is "beautifully strange." To begin, Khris, Michael, Jay, Kallie, Jill, Charlene, and Karen share their experiences with personal trainers, the public, coworkers, and even a neurosurgeon, where they faced misconceptions, "snarky comments," "staring," ignorance, judgement, and disbelief. This resulted in "feeling self-conscious," unseen, "shame," "frustrated," "passive aggressive," angry, "like you're gross," or "having to prove that you have CF or how sick you are." It is worth noting that both Michael and Kallie have struggled with their CF identity, which will be expounded upon in super-ordinate theme 4. CF and sense of self/identity, and that Kallie's "shame" may come from internalizing the judgement of others. It is noteworthy that Karen is disbelieved when she has had neurosurgery and at her most vulnerable. It speaks to her strength that she can advocate for herself nonetheless:

Khris: Yeah, so I did stop training with her. She didn't really understand what I had. I guess she had never heard of it. And trying to teach somebody something or explain it to them when they can't see it. It's like Doctor Seuss. Just because you can't see it doesn't mean it's not there, right? So, you know I would start coughing 'cause it was pretty hot this summer … and she … didn't have a poker face, so she kinda made a weird face … And last thing is because CFers can be so tiny sometimes and you know with the GI issues I've had people ask me if I'm pregnant, because I'm so full of shit or full of backed up … So it was, you know it makes me self-conscious… And I hate to bring politics into this but Trump …you are literally setting us back. We have worked so hard to end the stigma and you have a man in power like this… So, you know it's definitely difficult when you can't see it, but you're taught in kindergarten just because something is not there, just because you can't see it doesn't mean it's not there. Horton Hears a Who we all read that book…. And I think for me it's the ignorance of people. And that impacts my CF a lot (81, 82, 83, 84).

Michael: So, the word CF people actually know what it is, but they don't know what CF is. 'Cause they kind of always went in the whole dramatic advertisement compared to the whole informational example, you would see a kid living in kind of like drowning … So, once you start talking all Oh, I have CF like Oh yeah, so you do this this, this and then you kind of like. Well, yeah, well, how do you know that? And then they say Oh I seen that guy on this show blah blah blah. I'm like OK so that's one part of it but see I'm like the total reverse and then you start conversations (85, 86).

Jay: And because it doesn't always present itself obviously to a lot of other people. The invisible illness type deal. You all of a sudden like oh what do you mean you were sick? Well, you know I had this thing. It kind of hits hard when it does. Lung functions drop 30%

overnight…. They don't quite comprehend like Jay's going to have a hard time doing this. But you're gonna ask him to bring the ladder up and downstairs three times anyway? (87, 88).

Kallie: I feel like the biggest problems I've had always been at school or at work. I'm like if you look half normal people just assume you're normal. If you're keeping up with the rest of your peers or your colleagues, people just think you're fine. And I, I've always hated starting a new job 'cause I know it always follows the same sequence … and I heard you talk about like the emotional maturity to speak up … hey, I cough because I have CF … I totally admire that…I feel like I'm not there yet because I still feel like kind of a sense of shame … Oh yes, like don't worry, I won't get you sick cause it's gross like again, people don't care why you're coughing, they care that you're going to get them sick … But it's a … chronic lung condition. Oh my gosh … but those kinds of conversations are the norm and are frustrating but necessary … The past few years I cannot for the life of me like keep on more weight than like 105 pounds. And it's impacting me so heavily and you get the snarky comments well wow like you must really eat just salad and it's like no bitch I'm eating hamburgers everyday all day and I still cannot gain any weight, so … you kind of … want to be like passive aggressive … Yeah, it's definitely a bit of a weird one with dealing with something that people can't see and maybe don't understand fully (89, 90, 91, 92).

Jill: Stop staring. I had some guy in the bus actually elbow me and then point at his mouth angrily like cover your mouth and I was like. You wanna go? (suggesting fighting with her hands) (93).

Charlene: I think when I was younger it was harder because of the coughing. I think like in the judgment that I would get with people. I think that has been the hardest part for me, of it being a non-visible illness it's that like when you cough, and somebody doesn't realize that you have an actual disability or reason for it they treat you like oh like you're gross, like you're sick you should go home. You shouldn't be at work, can be at school. So, it's always having to justify that, and I think like when I was when I was younger, I didn't have that like emotional confidence … being like, OK, let's educate them on this (94).

Karen: When I would talk to my neurosurgeon he would be, well, you don't present like my textbook and I was like, Yeah, but I'm not lying. I promise I do have CF. He's like, well you don't look like it … But I had situations where I was post op. I was in my room. I had stitches, I was shaved, and I was having to fight with the nurse to have my CF meds sent up because I was in the neuro ward not the CF Ward… they didn't believe me … And so then I had to advocate for myself when I was still trying to be coherent as to what was going on around me, because of where I was cut here. So, my eyes, like I was swollen all around here (points to her head). Here I was having to fight for myself because they're this is what you need. I was well … And having to essentially be let me teach you …I have to make sure that I'm on top of that because I don't have full confidence that I'll be taken care of unless I do … I find that it sometimes brings a little bit of aggression out and being like I need to define this for myself, I need to be in control … The other kind of component with … CF being non-visible is sometimes … especially when it's come to work situations where … I was applying for a job like that was quite intensive and I was honest in the interview… there may be times where I will have to take two weeks to be in the hospital. And … my employer was OK but then what does that look like for productivity? And so

> … it's proving how sick I am, but then also be like there's ways to manage through it (95, 96, 97, 98, 99, 100, 101).

Jay, Karen, and Michael speak to people needing to understand that "there is a middle ground," that whilst you have limitations you also can push through. Best for them to trust your judgement, "walk this together," not make assumptions and ask directly:

> Jay: With an invisible or non-visible disability, it's not that obvious. There might be something wrong. There might be an issue. There might be limitations, so that's … hard to get across. And I find that one once people see me in a bad day. Uh, it kind of flips 180 where they think I can't do anything. Like Oh, he's a sick one. Don't ask him to do anything he won't be able to do it …they flip over to he's a disabled person. Uh, so it's hard to. It's all or nothing … You know, so there's no real middle ground …It's very difficult to find that balance of like, well, I can do a lot of things just if I tell you it's too much (102).
>
> Karen: And I think that's one thing when it comes to the non-visible component is people are like this is what you need. It's just because you think it's what I need does not necessarily mean it is and that sometimes happened when meeting with friends where we'd be going for a hike and I'd be huffing. And they're like we can stop if you want to. I'm like no, I'm fine like my lungs are feeling good. No, no we can stop. I have stuff for you if you need it. No, no, no, I'm good so just kind of that being like I'm not trying to fight you on it, it's just I can make the decision for myself. I appreciate … that you're trying to be mindful of my limits, but at the same time though, too, we need to kind of walk this together … it's what you were saying Jay, with CF not being necessarily visible people don't necessarily see it's possible to have middle ground (103, 104).

> Michael: I always pride myself to try to not use CF as a crutch … I'll let you know if I don't feel good. I've been telling [my entourage] I'm an open book … instead of assuming shit come and ask me and I'll tell you right away. And it's a lot … easier than you assuming a bunch of stuff. And I find it's the same thing, but like cancer people that have cancer that we usually have this prenotion of what they are, but just talking to them, it's the greatest thing ever because they are experiencing it. And you're not (105, 106).

Charlene, Jill and Kallie distinguish between having a visible illness/disability versus a non-visible illness/disability in that "when in a wheelchair people automatically make assumptions" but "having a non-visible disease …. you can fly under the radar …you are able to decide" (107, 108, 109). Charlene speaks to "having the opportunity to be able to hide it," to have an element of control, for example, when dating:

> So, the fact that it is non-visible sometimes I do have the opportunity to be able to hide it when I want to, and I do see that as something that I'm grateful for because there are certain contexts in which I don't necessarily want to present it right away, or that I might want to take the time for example, like when dating. I'd much rather present it like the way that I want to present it, or in a way that's under more my control (110).

Jill has found that "being open" about her CF has served her well over the years, however, she relays an early experience where her mother and teacher, likely trying to demystify CF for her classmates, reveal private "habits" without her consent. This had been "mortifying:"

> So just living with it on a daily basis, like I was always very open with it. Oh my God in grade school, my mom, organized something with CHEO to have the nurses actually come and talk about what it is. So, my whole freaking class knew everything. There was even something about like CF kid habits in the bathroom. Which is mortifying. When you're in

> like third grade. Anyways (Everyone laughs together). Oh my God, it's the most mortifying. I have distinct memories of sitting there. I'm like, Oh I didn't know this is in there (111).

Finally, Khris conveys people's reactions when her CF is visible. She seemingly internalizes this by refering to her body unfavourably and then, possibly in an act of defiance, sees herself in a more complimentary light:

> The non-visible part … you know for me once I put on a bathing suit you can see all my scars. You know I've had a bunch of tubes, Portacaths. So, once I take off my clothes and I'm in a bathing suit you can see. So, people obviously you know it's like Frankenstein or bride of Frankenstein whatever. And they obviously like whip their heads … Even though it's invisible, you know when I get sick, I'm pale. My glands get swollen. I have a blood clot in one arm … But these are things that not many people will catch onto. They just think I've got a strange body. I do, but I mean, it's beautifully strange, I assume so (112, 113).

4. CF and Sense of Self/Identity. As co-researchers discussed their sense of self in relation to CF at various points throughout the focus group, it became evident that Michael and Kallie were still grappling with accepting CF, whereas the others were "further along the path" of integrating CF as identity. Both Michael and Kallie, in "pushing away" their CF to a large degree, had repercussions in terms of their physical health. For example, Michael sees himself as "pretty much a normal person," the "sick non sick kid," and "this means that [he is] pretty bad at taking care of [himself]." Kallie admits that she "struggle[s]a lot with the acceptance side of it and that kind of impacts the physical side of it too." We learn that Michael and Kallie have been "in relatively good health for a good chunk of ... life" and only recently as they are "getting older" have had to grapple

with their health declining. This in part may explain their reluctance to be defined in any way by their illness as feeling physically vulnerable is new and not yet integrated. Aesthetic and existential anxiety (please refer to page 38 for a definition) may play a role in that neither one cherishes being viewed as disabled and devalued (Lingsom, 2008; Stone, 1995). Khris and Jay, on the other hand, have struggled for some time with their physical health and see themselves divided between two worlds, "too healthy to be in the sick world … too sick to be in the healthy world" and "in between disabled and able," respectively. Jill accepts having a "physical disability" but bemoans CF not fitting into the disability category on applications thereby missing out on essential grants and bursaries. This is "one bad thing" about having CF (114). Karen does not weigh in a great deal regarding CF and sense of self and identity, except to reference her experiences when on the "neuro ward" and in the workplace, where it became essential to "define CF for [herself] so that [she] could explain it to others" (115). Charlene talks about coming to terms with death as integral to accepting and understanding CF, stating, "once I was able to kind of process [death], I definitely felt a lot more at peace." In having dealt with ill health for a very long time Charlene may have learned to cope with the existential distress and spiritual issues of those with CF, such as feelings about death and dying and learning to feel in control of one's situation (116, 117). Charlene's experience recalls the study of Trandel et al. (2019) where the authors find that the five most common unmet existential needs amongst participants in their study, particularly those with moderate/severe symptom burden, were fears of CF worsening (50%), uncertainty about the future (39%), worries of others (34%), learning to feel in control of your situation (29%), and death (24%). Though the authors do not bridge feelings about death and learning to feel in control of one's situation, they recommend that providing support for these unmet existential needs could

improve their quality of life. They recommend palliative care as a viable mechanism to provide this support (Trandel et al., 2019).

Where co-researchers situate themselves in relation to CF, self, and identity, is reminiscent of the study by Horky et al. (2017), showing that CF played more of a role in the identities of older and sicker adolescents. Importantly, that study also showed that CF identity can be fluid and therefore it is imperative to make no assumptions. In the narratives that follow, we witness the evolution of our co-researchers regarding CF and their sense of self/identity:

> Michael: I'm pretty much just as a normal person that I call myself … I am the sick non sick kid so I have CF but I don't live like I have CF and … it has a lot of repercussions, meaning that I kind of really bad at taking care of myself … maybe it's the whole mental part that I need to fix a bit and so that's the biggest hurdle is living like you have CF … This son of my cousin has CF … And it's kind of getting depressing to the fact that every time that people talk to him it's about CF. And every time that he wants to do sports, it's always you gotta do sport if it fits with CF … it's pretty hard for me to see …I didn't have that empathy [for people who got sick because I wasn't living like that] … and now that I'm getting older, I'm kind of find that I am getting it (118, 119, 120, 121, 122).
>
> Kallie: But definitely one of the biggest things that I struggle with is … this kind of sense of normalcy … Like, yes, I do treatments. Yes, I cough, but I have a job. I have a partner, I have dreams. I have aspirations. And then you go to your CF appointments and it's like how often do you do your treatments? Like 70% of my hospital visits end in tears … I think a lot of it is mental for me …. So, I think I struggle a lot with the acceptance side of it and that kind of impacts the physical side of it too … I feel like I've over the past three years have started really going downhill and starting to see really like the bad things you don't

want to be having when you have CF … it doesn't define me … but it's really been something that I've had to confront much more deeply … And it kind of came while I was traveling by myself in Europe, and I could barely lift a suitcase, like up and walk it up a flight of stairs … and I literally just sat at the bottom of the staircase crying … and I kind of knew I had to start taking it seriously (123, 124, 125, 126).

Khris: Like I said earlier, I'm too healthy to be in the sick world then I'm too sick to be in the healthy world … as much as I don't want CF to be my identity, it is. Unfortunately. It's when my family looks at me. I'm the sick one, right? … You know, a lot of people in my family claim that I use CF as a crutch. Hell yeah, I do (127, 128, 129).

Jay: My lungs have taken a big plummet for the last couple of years there, but when I was younger, I was a lot healthier. So, I kind of got used to being a healthy sick kid, you know. Like Oh, I got this thing, but it's not really a big deal. And now it's a lot like well, don't do too much, you'll burnout … But it's that being in between. Kind of like I'm going to try and strive for a career all these future things and ... Like I could still do stuff I could still do some work, limited as it may be … So, I'm not disabled, I'm able, I'm in the in between and that's really hard to fit in a system that's not designed for it (130, 131).

5. CF positive aspects and meaning and purpose in life. Finding the positive aspects to CF as well as its meaning and purpose was a topic of conversation for co-researchers throughout focus group three. All weighed in except for Kallie which may be related to her "struggles … with the acceptance side of it" and thus a reluctance to view CF as constructive. Finding the positives in one's illness experience as well as meaning and purpose can ameliorate negative emotional states and have health related benefits in persons with progressive and/or acquired non-visible illness/disabilities (Carroll & Coetzer, 2011; Dezutter et al., 2015; Graham et al., 2008; Livneh &

Antonal, 2005; Patterson & Staton, 2009; Psarrra & Kleftaras, 2013; Schleicher et al., 2005; Smith & Zautra, 2004). The responses of co-researchers call to mind Viktor Frankl's concepts of freedom of will, will to meaning and meaning in life (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Frankl et al., 2010). Karen and Khris, for example, observe that CF has made them more empathetic, and Charlene and Karen note that CF has meant an acute focus on priorities (choosing one's attitude and finding meaning in the moment). CF "really puts a different colour glass through which you see your life." Therefore, co-researchers spend time on "things that are worth it," "making the most of [their] time" with people that matter, "having no regrets and focusing on things that bring joy," setting goals that are "reasonable," "being happy," "making people laugh," and feeling a "little bit of pride … because you've earned it." Charlene speaks to "planning your life goals or your career goals as a constant existential thing, especially when it comes to aging" because having a longer life expectancy is a very new concept to those with CF. Michael likewise refers to aging, "the whole getting ready to live longer than what you always expected when you were a kid." Jay's "arrogance of health" is such a profound statement because none of our co-researchers can take their health for granted, and this influences most of their decisions:

> Charlene: Appreciate the time that you do have … I think that's one way that I … kind of … cope … the free time that I do have. I focus on … spending that time on things that are worth it for me or that make me happy … Planning your life goals or your career goals that's just a constant existential thing to assess, especially when it comes to aging with CF because there's been such … a change in the last 20-30 years … for the CF community … In terms of my sense of purpose or meaning in life … I definitely do feel like I'm more comfortable with the concept of death and kind of having my life priorities … that I got from living with CF (132, 133, 134, 135, 136, 137).

Karen: With CF is … this notion of time and I want to make the most out of my time while I'm healthy because if when I get to the point where I'm not, I don't want to be sitting there angry with myself on the couch being like I wish I did more with the time … But in terms of like sense of purpose and meaning …. I think following kind of the past couple of years I held a lot of pain in and what really kind of released me from it most recently was my nephew came to stay … and being able to play with him and wanting to be present for those moments … another thing… so for me I would say I think that having CF has equipped me with just a very developed sense of compassion and empathy (138, 139, 140, 141).

Khris: Something someone talked about regrets you don't want to be on your deathbed talking about regrets, right? So, I think that's my biggest thing is when I make a decision when I travel, whatever I do I go is this going to bring me the joy that I'm looking for? Is this going to make me feel more of a person? If I'm going to give a positive to CF I'm going to say like Karen, empathy (142, 143).

Jay: But what I find is that [CF] makes you a lot more aware, your general awareness of what's going on and you're just humbled …. by things more. You know? Just keep that in mind that you want all these things … but you have this thing you have to consider so that if there's a positive aspect it's the being humbled and not getting you know, too big in your britches … hey, let's keep it reasonable let's keep it real. What can I not do as opposed to … have that arrogance of health (144, 145).

Michael: The whole getting ready to live longer than what you always expected when you were a kid … And the whole … what I want for life … is I just wanna be happy and make people happy so that's pretty much the biggest thing … I'll be with friends or with people

> and I'll just make a fool out of myself because I don't care just ‘cause it makes people laugh … But it's all part of the whole I live like I don't have CF so it's always different with the whole what I want in life depends day to day (146, 147).
>
> Jill: CF has really made a lot of things that maybe people take for granted … it gives you … that little bit of pride, you know every year, like you know, all those times, I didn't want to do my treatments. I didn't want to take my pills. I didn't want to go exercise. I didn't want to do any of that stuff, but like you know I did it and I'm here … and as for sense of meaning and purpose in life like … whenever something good comes along, it's like I did my best to get here and now I get to enjoy it … it really puts a different colour glass through which you see your life (148, 149).

Finally, when contemplating their purpose and meaning in life, Jay and Khris speak to the brutal reality of falling short of society’s expectations regarding gender roles and fertility. When Khris’s distended belly is misinterpreted as pregnancy by a nosy bystander this reminds her of her issues with fertility and brings on “rage,” which she represses due to gender stereotypes:

> Jay: Fertility somebody touched on fertility, I don't presume to know how it affects the female body. But I'm very aware of how it affects the male body. And it's not pleasant … If you're young enough and you think, oh yeah, I'll have kids once I find the right person and all this other stuff you have this image in your mind of what you want to achieve. And then it's … by the way, 98% of male CF patients are sterile. So, here's this on a platter. Deal with that (150).
>
> Khris: So, day to day chores … once again as a woman, that's what I'm supposed to do, right? Especially if I don't work … and … you know where we're told in life as a man and a woman you're supposed to procreate? Or what are you? You’re pointless … I went to

> Starbucks and got a coffee, and the woman goes you shouldn't be drinking coffee pregnant. And I had so much rage (my stomach was distended because of GI issues) that I wanted to spit at this woman. But I couldn't because once again in society as a female you have to be kind and sweet and rainbows and all that (151, 152, 153).

6. Observations and Recommendations: a) CF Counsellors/ Psychotherapists-Attitudes, Knowledge and Skills; b) CF Doctors, Nurses, and all Allied Health; and c) the Healthcare System. Focus group three's sixth super-ordinate theme is divided into three subsets, inclusive of observations and recommendations for the healthcare system overall. All findings have been incorporated into the Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

6.a Observations and Recommendations for CF Counsellors/ Psychotherapists- Attitude, Knowledge, and Skills. Having engaged with one another on many topic areas regarding their experience of CF, co-researchers turned their attention to observations and recommendations for CF counsellors/psychotherapists, which shall be elaborated upon here. This super-ordinate theme and subset are further divided into the following areas as in focus groups one and two: attitude, knowledge, and skills in accordance with Topic Guide questions five and six and the expressed needs of co-researchers.

Attitude. Discussions regarding necessary counsellor/psychotherapist attitudes so that co-researchers could "feel trust" and "open up" focused on several central ideas. Empathy was thought to be an essential quality, particularly as a counterpoint to the judgement that many have experienced at CF clinic appointments. For example, Jill states, "you get to clinic and they're like why didn't you do this? … It just kind of breaks you down. We need someone to be on our side … when they get nice and gruff with you" (154). Khris agrees with Jill regarding the need for

empathy as a counterpoint to "doctors and residents who are stone cold. There's no facial expression there" (155). The two also discuss another important quality, "thick skin" because, according to Khris, "sometimes I'm gonna want to blame somebody…and sometimes it's the therapist that's right in front of me" (156, 157). Karen has had the experience of her "dark humour" being off putting to some and concurs that having a thick skin on the part of the counsellor/psychotherapist is an essential quality (158). Michael rounds out the conversation by stating that empathy is important but that he also needs a counsellor when he is "being too dark ... too on the devil part …to talk to [him] straight into the face and ask is this adaptive?" (159). Accordingly, the "gentler" quality of empathy is important but so too the "stronger" qualities of having a "thick skin," and confrontation when required.

This leads to a conversation about counsellor/psychotherapist as "ally" which is important to "establish a crucial bond of trust" because "being a human being is tough but being one with a degenerative chronic illness is tough too" (160, 161). An ally is somebody who is going to "stand beside [us] when things get tough ... because you may help [us] to find comfort in dying, you may help [us] to find peace in this life" (162, 163). Khris, Charlene, Karen and Kallie see being an ally also as someone who will "look at [us] not just as a disease … but as a real human being … with other problems that [we] might want to consult for" (164, 165, 166, 167). Kallie states this well:

> It's really important that the counsellor is able to differentiate that I am not the disease and maybe if I'm there and having challenges, they stem somehow from CF, but that's not the only thing I want to be there to talk about … So, I was recommended to a therapist a little while back … and it felt like every issue I was raising it was OK let's talk about CF. And it like made me so upset 'cause I was, OK there is more to me than just CF. It is an overarchingly large theme .. but also …there's an overarching theme of like wanting to feel

> normal and as much as your health, your physical health is important you kind of sometimes just want like a bit of an escape from that. So, for me, it's understanding that it's a bit of a fine line (168, 169).

Finally, other coveted qualities on the part of the counsellor/psychotherapist include being "transparent" where appropriate and "cooperative in the process," "acknowledging that you can't fully understand …that you're not an expert in my experience of chronic illness" and ensuring that people's issues get addressed "within a reasonable time … that they don't fall through the cracks" (170, 171, 172, 173). Charlene speaks to her personal experience with the latter point here:

> I haven't had that many terrible emotional experiences in my life, but one of the few times that it did happen I did reach out for support, and I didn't hear back … that had like a huge negative impact on how I dealt with that difficult period in my life. It definitely impacted it for the negative for sure, because it made me feel I reached out to the supports that are supposed to help you and they don't end up helping you. So, ensuring that like if somebody requests support that they actually do get it as opposed to falling through the cracks (174).

Knowledge. In addition to understanding that "CF is a spectrum which effects everybody differently and changes day to day," co-researchers in focus group three want counsellors/psychotherapists to "know more about CF not what Wikipedia tells them" (175, 176, 177). It would also be helpful, according to Khris, "to have a passion for CF …to get angry when we get angry get sad when we get sad" (178). It is imperative to understand "about mental health and CF," "have knowledge of health issues … and relevant resources" and to provide guidance through the complex legal and financial implications of having the illness (179, 180). To know more than the Wikipedia version of CF it would be beneficial when training new therapists "to

come to CF clinic especially on Fridays" when there are few people there and "they're basically doing it alone" (181).

Counsellors/psychotherapists should also be aware that many with CF experience the "burden complex … not wanting to burden other people, but also needing to figure out how to ask for help." Likewise, they should "not assume that because [they're] healthy physically that [they're] healthy emotionally" (182, 183, 184). Finally, counsellors/psychotherapists should understand that persons with CF can be open to learning about their illness but also are experts in their own experience and "be willing to turn over the reins." Jay explains this well:

> So, there are aspects that we might not know. I mean, we're pretty good. But then once in a while I go shit there's another thing. Like for me, the fertility thing kind of took me off guard 'cause like until that point, I thought I had it covered. So, knowing that CFers might not know everything but they are open to … learning more about what they have and what could be affecting them … We're also the experts. And it's … finding a therapist who's willing to kind of turn the reins over to us because we are the ones that know the most about what's going on in everything (185, 186).

Skills. When it came to discussing the skills of a counsellor/ psychotherapist of primary importance to them co-researchers in focus group three had lengthy and substantive answers. All but one, Jill, on the socio-demographic questionnaire had indicated that they had previous experience in counselling and psychotherapy, and this is perhaps why their answers have such depth, they are founded in their experience-based knowledge. This researcher will attempt to present their views concisely here, as they move from the more general to the very specific. More generally, Jay, Khris, Charlene, Karen, Jill and Michael speak to the importance of the counsellor/psychotherapist not talking in platitudes but helping them in a meaningful way, walking

beside them even when things get uncomfortable and breaking through their defenses when appropriate. Even after having marked "no" to previous experience in counselling and psychotherapy, Jill weighs in regarding the importance of "having a personalized approach" with individuals with CF instead of "the standard here's my outline of how I'm going to deal with these patients." Michael continues with this theme, stipulating that "predetermined questions" have never resonated with him. Instead, let's have a meaningful conversation about what matters to me." Co-researchers find it helpful when a psychotherapist "pierces through I'm fine as a default," allows for "a conversation about the gross and uncomfortable," helps them to "face things," and "knows where the boundaries are, when to push and get to the touchy, dark stuff:"

> Jay: What I would like to see in a counselor is … I've had experiences where you kind of just talk to them and they're like, Oh yes, OK, thank you. And there's no, there's no pushback. There's no dialogue. So, I tend to have this brave face on in public like Oh, I'm fine. I've got this covered. And it's something I default to when I meet new people. If I meet a new counselor, I can kind of just keep that all I'm fine kind of face and now everything is kind of OK. I got a lid on everything. I need someone to pierce through that and call me out on my bullshit … and then [eventually] let's get to the root, let's try to fix the overall problem (187, 188).
>
> Khris: I'm not here to be your friend. I'm here because I need your help, I need your guidance … I want somebody I can't speak for anybody else, but I want somebody that's going to talk about the uncomfortable side of CF. You know I want to talk about my stools I want to talk about my mucus… I need a counselor who's got thick skin and not you know will not abandon ship when it gets hard … [when in emergency] and everyone's coming in and poking and prodding, I would need a therapist who is gonna sit down in a chair and

talk to me. Not at me. I want to have a conversation, you know, and I want them to say like OK so how are you doing? … And I need a counselor who's gonna take the gross the uncomfortable and work with me even if I push him or her away. Come back tomorrow. Let's try it again. (189, 190, 191).

Charlene: For me, it's important for a counsellor to not just use reflecting … it's nice they have those positive thoughts about you … but it makes me feel like they are disconnecting themselves from us because they are seeing you for what the stereotype response is, as opposed to what you're here for or actually need … so what I do prefer more of like a structured approach, when like counselors have like a plan … what they think would help push forward as opposed to just being listening and empathetic … Also, I can share as well that what I find most positive or helpful in counselling is when you get to a point where you're forced to face things that you were afraid to face or things that you weren't necessarily aware of for yourself (192, 193).

Karen: Going to see a therapist I got a lot of … you're such an inspiration for what you're going through and I'm like those words are uplifting …but what I need instead is that's a lot of shit to carry. What do you do to self – care? It's like the hero complex where people feel the need to like with people with disabilities … you're an inspiration … And I would say the other thing is asking the question of where the boundaries are, where can they push and where for right now they can't push and understanding the fact that eventually those lines will need to move … because we do talk about the dark stuff and it's important too … so making sure that that's an ongoing conversation … but ultimately the visual that comes to mind is I need a counsellor who's willing to walk with me, not yelling after them to catch up (194, 195, 196).

> Jill: I think it would be important to have a personalized approach to people 'cause I mean just the standard here's my outline of how I'm going to deal with these patients, doesn't fit it, doesn't work. You can't have just platitudes and cliches answer to everything that you're not going to get anywhere, especially for people with chronic conditions like us who like it, it's not our first barbecue. We've gone through a lot of stuff, and we've probably had to visit a whole bunch of services before and to acknowledge that … we're kind of in a separate case because we've been through the health system before. So, to have a more personalized and cognizant approach that you know we're fairly knowledgeable as a patient group about what is affecting us … there's no one size fits all treatment (197).
>
> Michael: I've been seeing my therapist, and that's pretty much the only experience that I've had with a social worker other than the social worker that would come into clinic and asking you some predetermined question that I already have predetermined answers. So, I never related to those people always like hi, how are you feeling alright? And, what's new in your life this and what are your plans for like? It was always like I didn't connect to them, and I just went through a separation and our nurse coordinator told me that she knows someone who is really good and that she actually knows CF and they said you know that the reason I want to meet her is for how I'm dealing with the separation but at the same time maybe I can put in some questions about CF and that's how it started (198).

Regarding specific skills on the part of the counsellor/psychotherapist for a session to "progress" and "be constructive" co-researchers cited the following: "being able to read body language," "being able to adjust to what's feasible for me right now," "having that balance between allowing us to feel [our feelings] and move on," "understanding when interconnected factors connect, when to focus on one thing and remembering the microdetails," "being gentle and

respectful with transitions," "providing one strategy to hold onto," "engaging in dialogue that is a push and pull that [facilitates] clarity," and finally, being able to conclude the session and end it on a positive note (199, 200, 201, 202, 203, 204, 205, 206, 207). Jay speaks to the importance of having an interaction where "you leave better off:"

> I guess with the ideal kind of meeting with a psychotherapist for me … they're going to push back … where they need to push and lay off where they need to layoff, and having that balance is hard for like just a regular conversation… It's an interaction … where you leave better off or in a better direction than when you came in…. and there's a bit more clarity… things are more defined (208).

6.b Observations and Recommendations for CF Doctors, Nurses, and all Allied Health.

Having discussed the requisite attitudes, knowledge, and skills of CF counsellors/psychotherapists co-researchers in focus group three turned their attention to observations and recommendations for their CF interdisciplinary team. Three main ideas developed in this regard. First, Khris observes that "prepping parents and patients a bit more" regarding what to expect with an aging CF body, for example, "coughing up blood," would have been beneficial, less surprising (209). Charlene turns to the notion of "struggling emotionally, even though [she] wasn't necessarily super sick," and not getting the support she required. She recommends that patients get "attention or support" if needed even if they don't appear to be "sick enough" (210). Finally, Karen and other co-researchers speak to the need for "group opportunities or therapy sessions," and she outlines her "dream sequence" for mental health/counselling services at CF clinic which means having options (211, 212):

> Karen: And I like this kind of group therapy. I think one thing that I would totally pitch would be … if patients had the option. I think there should be full time services in clinic.

> But if I had to pitch … the dream sequence the clinic offered do you need one on one sessions, or would a group therapy session serve you better? Cause some CFers find they do better in community sharing. Others need the one on one and I think if both of those options were offered to me when I came into clinic, I'd like the idea that it's not one or the other. It's that both exist in the first place (213).

6.c Observations and Recommendations for the Healthcare System. This super-ordinate theme and subset is unique to focus group three and centres on the observation that the healthcare system is "not made to deal with chronic illness that can be acute sometimes." Charlene touches on self-advocacy whilst Jay talks about "trying to explain" the capriciousness of his condition. There is a call for "healthcare to be a joint decision" and for systems to be more accommodating of nuance. The locus of control appears to be internal versus external:

> Charlene: I agree with the advocating for yourself component. I think it's very important when people have serious health issues. And I think it's important for healthcare to be a joint decision, not just what the system says that you should do … I think the hardest issue with living with CF has been dealing with the more systemic side of things like medical insurance coverage or getting access to medication like CF modulators. You know, we all know that that's a huge issue … I'm having to fight [for access to] something that's not built into the system yet. And … I was denied disability because … I was working part time hours and … the system isn't made to deal with chronic illness that can also be acute sometimes (214, 215).
>
> Jay: CF is one of these, you could get really sick really fast. Even though you're doing well overnight, just dropped lung functions and you're feeling horrible. There's not a position for can I get half benefits for working part time? Can I get a little bit of a cushion if I fall

> sick all of a sudden? And there's a whole work dynamic or school, depending on what applies … Oh hey teacher, you know I'm going to miss the next two weeks, cause I'll be in the hospital doing a lifesaving treatment that if I don't do, I'm going to die in three weeks. Because I'll be choking on my own breath. Recovering from that. That's something I've had to practice a couple times unfortunately, just drop out of class or school or work, or just try to explain that (216).

7. Counselling and Psychotherapy Experiences: a) Helpful Experiences and b) Unhelpful Experiences. This super-ordinate theme aligns with Topic Guide question eight and, like super-ordinate theme six, informs the patient-centred framework (Appendix H). Two co-researchers in focus group three shared helpful experiences whilst three shared unhelpful experiences. Both shall be expounded upon here.

7.a Counselling and Psychotherapy Experiences - Helpful Experiences. Charlene and Jay relay their helpful experiences with a counsellor/psychotherapist where the common element seems to be engaging in reciprocal dialogue:

> Charlene: The most positive interaction that I've had with a counsellor was just because he was being so authentic and more of … a conversational approach, and you know more like a human being where it … wasn't like somebody who's an expert telling you what to do … (217).

> Jay: On the other hand, a really great experience is more recently with my therapist. I think I've connected with her enough. That she has a better approach to dialogue. You know back and forth pushing on certain issues, letting other issues go. So, it's a more nuanced thing (218).

7.b Counselling and Psychotherapy Experiences - Unhelpful Experiences. Jay, Khris and Karen speak to unhelpful experiences outside the hospital, whereas Kallie unpacks an unpleasant memory with a therapist at CF clinic. Tellingly, as Jay recounts his unhelpful experience, he begins by saying "the catharsis of this might help." This seems to be the common thread running through all our co-researchers' accounts. There is a theme of feeling discounted and needing to collectively cleanse themselves of this experience. Whether Jay is talking about a psychiatrist as "drug pusher" bent on helping him to numb his feelings rather than get to the "root of it" or Khris is referencing the "Wikipedia" knowledge of counsellors "who don't deal with [CF] personally" or Kallie is remembering the therapist who came in and failed to understand that she might not want to talk that day because of a bad pulmonary function test (PFT), this is all said with intense feeling. Karen too recounts fully five unhelpful experiences, one graver than the next, with great consternation. She talks about not feeling believed, someone telling her she "should be happy to be alive," having to cope with "astronomical wait times" when in need, "the feeling like therapists just want to get paid," a sentiment also expressed by Khris, and paying for the "administrative component" of a session rather than getting to anything substantive. The unhelpful experiences of our co-researchers recall the sage words of Jay, "the arrogance of health." They are a clarion call to counsellors/psychotherapists to listen, to believe, to serve with humility:

> Jay: I have had a few unhelpful experiences and I think the catharsis of this might help … A psychiatrist that was a drug pusher didn't really want to address the issues didn't really want to well, what's going on here? Let's fix this. And while we lean on this medication as a crutch while we figure things out. That wasn't really his approach. It was how do we chemically fix you so that you're not in pain? That was a really bad experience … I'm not trying to downplay the advantages of maybe having some medication or some chemical

treatments for anxiety or depression, I think those have a place. But having those without the other component of why it's happening (219, 220).

Khris: The fact that outside of the hospital, a lot of these places you do only get covered for a certain amount of sessions. So … sometimes it does feel like they just want to get paid as awful as that sounds. And … it's difficult because a lot of these counsellors are very Wikipedia CF right. They don't deal with it personally they don't. That's not their expertise … it's just mental health and like Jay was saying pill pushers (221, 222).

Karen: I would say two sentences that immediately turned me off a counsellor are you sure that's really how you feel? Are you sure that's what you're feeling? We can work it out and say how would you expand on it, but if I immediately feel like you don't believe me? Then I no longer feel comfortable talking to you … But the other thing is well, you should be happy that you're alive other people have died younger than you. So, like that's one thing to where it's like, so crushing because it's like I understand that I should be happy that I'm alive, but that also doesn't mean that just because I've gotten to this point that everything's sunshine and rainbows … The other thing that I found with counsellors outside of the hospital is the astronomical wait time where it be like, yeah, I can take you for an hour here and then I'll see you in six to seven weeks and I'm like I need a little bit more than that … The other thing is too … most touched on was sometimes it does feel like therapists just want to get paid … And I had a covered appointment that ultimately was awash for me because we talked for the last 10 minutes because of going through all the documents. I realize there's an administrative component, but that to me was, alright well, that was awash and I left as a result (223, 224, 225, 226, 227).

> Kallie: One experience that I've had that turned me off … It was at the CF clinic and there was a therapist who showed up and it was just a day when I was not ready to talk, and they showed up and they come in and they open the door. Hello, can I come in? And I said sure why not and they start asking questions. And it's like I'm answering them and I'm being as polite as I can in terms of giving short answers … so I think it's great to have someone who's there but it's also … important for somebody who can recognize that maybe I don't want to talk that day 'cause I had a really shitty PFT. Maybe I don't feel like making small talk that day and just knowing that there is a spectrum of some days are really good and some days are really bad and being able to recognize that (228).

8. Feedback and Suggestions re: PAR Methodology: a) General Comments and Dissemination of Results; and b) Fostering a Sense of Community. Super-ordinate theme eight is divided into two subsets, based on the section of the Topic Guide: reflection questions on methodology used in the research. The first subset reflects answers to questions 10 through 12, whilst the second subset evolved from observing the sense of community that developed between co-researchers engaged in PAR. This researcher shall elaborate on both subsets here.

8.a Feedback and Suggestions re: PAR Methodology - General Comments and Dissemination of Results. General comments from co-researchers centred on the same theme, the requirement that the framework be developed by persons with experience-based knowledge, not "just on science" or doctors who do not know as much about their bodies or what they need. CF is a spectrum with "different mutations" and symptom presentations. Those with CF are "a different kind of sick" and know innately what works for them. Therefore, as Jay stated, "being included makes sense because you're looking at a spectrum of possible and probable things … and there is overlap …and differences … how can you get a good view of what's going on unless [we] tell

you?" (229, 230, 231, 232). All in focus group three also agreed that by using PAR, we were capturing what we were after in this study- developing A Patient-Centred Framework for Counselling and Psychotherapy with Persons with CF. Here, Jay talks about why PAR "makes sense" and Charlene speaks to her experience of being incorporated into the process early on. Her words recall Yardley's (2000) concept of coherence in that PAR exemplifies democratization in research. Charlene feels that her answers matter, that her opinions matter in the development of the framework:

> Jay: And having this high and mighty well, we're going to study this from afar doesn't really make sense. It's maybe a little too clinical. It's too mathematical. We're messy people. So, it just makes sense to include focus groups. You need that feedback. Because I think we've all learned the doctors don't always know what they're doing. At least a few of 'em don't. They might mean well but if I tell you I need a picc line I probably need a picc line. So yeah, makes sense to be included (233, 234).
>
> Charlene: In terms of the framework, I really liked the idea of incorporating us in the process, especially early on even when it was just you know, talking about we're thinking about doing focus groups. What do you think of that? Or how do you think we should do that? You know, you guys were like actively asking for our input and I really appreciated that … Um, sometimes I feel like people don't necessarily voluntarily tell people what they need, especially when it comes to counselling and mental health. It's good to have the practitioners actually … try to encourage that out of us because it's not necessarily always easy to say Oh, this is what I need. I think that this is what you should try to do, right? So, the fact that you asked us for that information also definitely made me feel like you guys

really did want our input. It felt like I would actually believe you that you care about our answers and care about our opinion. (All nod together) (235, 236).

The topic of sharing the patient-centred framework with other CF patients at the Ottawa clinic and requesting feedback from them before finalizing it, did not generate discussion. However, Karen insisted that "bringing in the [CF clinic nurse coordinator] was crucial" to the framework because "if the doctors aren't listening to us …. the nurse practitioners are … we need them" (237). Khris also thought it a good idea "to have clinic involved … let them learn from us … so future patients can avoid some of our hiccups that we've gone through" (238). Co-facilitators then weighed in about their experience. Charlene "definitely had a really good experience … but could have benefited from a little bit more structure in terms of what the expectation was for co – facilitators" (239). Kallie "really appreciated being involved in building up the framework" and was pleasantly surprised that in co-facilitating she got to both ask and answer questions, "it was great facilitating I was kind of worried at first that maybe I wouldn't have a chance to participate or share my thoughts as much, but I didn't feel like that was the case at all" (240).

Finally, regarding the dissemination of results, Charlene thought it a good idea to "present the framework to the Ottawa CF community" in part as a means to communicate with one another (241). Karen felt that any communication regarding the framework to patients needed to have "a visual and formatting component" and then a document attached should they want to read further. This would make the framework stand out as opposed to the myriad of emails that "are a mass clump of text" (242). Jay was concerned that dissemination of the framework be credible and substantive for CF psychotherapists. He proposed the following:

Jay: I think that publishing this in a journal would give [the framework] that kind of credibility and give it that whole clinical background of here's what we did. Here's our

> research method. But I think if you're going into psychotherapy, you almost need an online class or something, maybe slides. I don't know something more than just a pamphlet 'cause there's a lot of ground to cover in this. You need more than just a little pamphlet or a little email … Hey, here's the do's and don'ts. And then you gotta give it a bit more structurally. Here's the outline, go into expanded documents as you can. But it needs to be more of a class or a small training session or something more than just here's you know, 10 lines about all this research we did (243).

8.b Feedback and Suggestions re: PAR Methodology -Fostering a Sense of Community. Many co-researchers commented on the benefits of PAR in fostering a sense of community, and as a counterpoint to the isolation they typically feel from others with CF. Some observations have been noted in super-ordinate theme 2.b Psychological impact of CF - isolation from others with CF (244, 245, 246). I will continue to give this theme a scope and breadth here. Co – researchers had many occasions of shared laughter throughout the focus group which usually occurred when "they resonated together about an experience." For example, Khris commented at the outset of the focus group that "there would be lots of coughing but, whatever, it's part of the gig" and "everyone laughed and really appreciated that" (247). Her statement was one of many that served to normalize their collective experience and at times add levity. Another example of an exchange of this nature occurred between Khris and Charlene regarding "coughing on purpose during COVID" to keep people at bay (248):

> Khris: If someone's too close. I'll cough more on purpose so they kind of shrug away.
>
> Charlene: You know what? I've started doing that too 'cause like sometimes people don't respect like bubbles. But then like if they think you're sick then they'll.
>
> Khris: They'll move away quite quickly.

Charlene: It's for both of our sakes (All laugh together).

All co-researchers expressed that the PAR focus group had been a valuable experience which had allowed them to resonate and relate to one another and was validating (249, 250, 251, 252, 253). Here is a sampling of comments:

Kallie: You raise some really great points. I really resonated with a lot of those … I think obviously a lot of … each person's experience can resonate with each of us. Again, it's really valuable.

Jay: I do recognize a lot of what I'm going through in a lot of other people's explanations of things. Thank you … This is amazing. How you can relate to everybody's experience by the way.

Jill: Yeah. Yeah, definitely a lot of things you guys said have resonated with me as well. For me it's like everything.

Finally, both Jay and Kallie saw their focus group experience as an opportunity to come together and collectively unburden. Kallie summarizes the sentiment of the group as follows, "I feel like we're all going to wake up feeling like ahhh exhale. Oh, it feels good." All join her in laughter (254, 255).

Summary Reflection Focus Group Three. Focus group three is distinguished by the synergy of co-researchers, recurring subject matter that generated robust dialogue, and its three-hour duration. These factors are interdependent and may be linked to the homogeneity of the group. All co-researchers have CF and are 24-30 years of age. They are undertaking the same developmental tasks – achieving autonomy, establishing identity, developing emotional stability, establishing careers, finding intimacy, and learning how to manage a household - whilst simultaneously navigating a capricious illness/disability. Recurrent topics include CF as spectrum

which appears in fully five super-ordinate themes and subsets (experience living with CF day-to-day - CF as spectrum, experience living with CF day-to-day – CF and the impact of COVID, observations and recommendations for CF counsellors/ psychotherapists, counselling, and psychotherapy - unhelpful experiences, and feedback and suggestions re: par methodology - general comments and dissemination of results). Other topics are likewise repeated throughout demonstrating their significance. Co-researchers endeavour to know themselves, to integrate CF as part of their identities, while finding their place in an interpersonal world replete with misconceptions. It is possible that co-researchers' strong alliance developed not only because of their homogeneity but as a counterpoint to "the ignorance of people." Collectively, they validate one another and significant aspects of their experience. CF is "a dark disease" but it has also taught them not to take their health for granted ("the arrogance of health"). The bond that developed was punctuated by collective laughter and a sense of unburdening. Co-researchers would like counsellors/psychotherapists to work with them on issues that matter, for multidisciplinary team members to prepare them for the progression of their illness and for health care systems to accommodate to a "chronic illness that can be acute sometimes." All need understand that there is a distinction between CF and who they are innately, that they are well-informed as a patient group and therefore the framework should be based on their experience-based knowledge. Through their efforts focus group three furthered The Patient-Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis.

8.2 Section Two: Focus Group Horizontal Analysis

Whilst section one highlighted the phenomenological experience of co-researchers within each focus group, section two will examine the commonalities and differences, where present, between groups with the hope of gaining further insight into the experience of living with CF (RD)

and their recommendations for CF (RD) counsellors/psychotherapists and other interdisciplinary team members. This researcher will begin by comparing the general characteristics, socio-demographic details, and group dynamics of the three focus groups and then continue through each super-ordinate theme and subset. [5] The hope is that in the end we will have a more robust picture of this study's findings.

8.2.1 General Characteristics of Co-Researchers

Focus groups one, two and three took place within 10 days of one another and approximately six months into the COVID 19 pandemic in North America. All meetings were held on MS Teams to circumvent cross contamination and infection. Whilst COVID had significantly impacted the lives of all co-researchers in every life domain, only groups one and three centred their conversations in this area and thus the super-ordinate theme and subset 1.g Experience living with CF (RD) day-to-day- CF and the impact of COVID, was created in these groups to mark its cruciality.

Focus groups are distinct in terms of the characteristics of co-researchers, who fall into the following categories: CFRD (group one), CF 39 + (group two), or CF 18 - 30 (group three). That being said, two co-researchers in focus group one were being monitored for CFRD and had not yet been formally diagnosed and two co-researchers in focus group two were 39 + and had formal diagnoses of CFRD, at the time of this study. This meant that focus group three was the most homogenous with all co-researchers falling between 18-30 years of age and further, within an age range of merely six years. This homogeneity could have played a role in the synergy of the group. Co-researchers in each focus group face unique challenges. For example, most in focus group one

[5] A comparative analysis of focus group PHQ-9 and GAD-7 scores is presented in Appendix L of this thesis.

have at least two diagnoses, CF and CFRD. Their lofty treatment regimens are evident in super-ordinate theme 1.a Experience living with CF(RD) day-to-day- symptoms and treatments. All in focus group two are at "the higher end of [their] life expectancy," and are navigating both the tasks of middle adulthood and end stage disease. They did not benefit from many of the treatment options of those in the younger groups. As a result, fully two co - researchers have had double lung transplants and one had been on the lung transplant list before Health Canada approved the CFTR modulator, Trikafta, on compassionate grounds. The implications of "having grown up in a different time" is delineated in the following super-ordinate themes: 1.b Experience living with CF (RD) day-to-day- interpersonal relationships; 1.h Experience living with CF (RD) day-to-day- Trikafta (this magic pill); and 2.c Psychological impact of CF (RD) - not feeling good enough. All co-researchers in focus group three are younger than focus group two and have had access to more advanced treatment options which may have positively impacted their quality of life. Still, they are faced with the capriciousness of CF, and this becomes a focus of conversation. This is elaborated upon in super-ordinate theme 1.e Experience living with CF day-to-day- CF as spectrum.

It is worth noting that co-researchers in focus groups one and three fall within approximately the same age range, the details of which are elaborated upon below, and must navigate the developmental tasks of early adulthood along with their illness. Both groups discuss managing interpersonal relationships and finding careers, for example. However, there is a disparity in the socio-demographic details between groups and the substance of their answers related to these subjects may be attributable to two factors: their differences in mean age – 24.5 (group one) and 28 (group three); and overall state of health. For example, in terms of employment status fully half of co-researchers in focus group one are in part subsidized by the Ontario

Disability Support Program (ODSP) with the other half citing "unemployed" or "student" on the socio-demographic questionnaire. Contrast this with focus group three where six out of seven are employed (full-time or part-time), with one co-researcher supported by ODSP. In terms of interpersonal relationships, co-researchers in focus group one reference family and friendships more than intimate relationships and the opposite is true for focus group three. Discrepancies in employment status and content of relational references may be explained by co-researchers in focus group three being older and more well established or, alternatively, are attributable to the comparative ill health and onerous treatment regimens of those in focus group one. It may be that health concerns for focus group one confound some developmental tasks of early adulthood at this juncture in their lives.

Focus group three is the largest group with seven co-researchers followed by focus group one with six and focus group two with five, after the departure of Dolores. Focus groups one and three were co-facilitated by two persons with CF (RD), with focus group two co-facilitated by one person with CF and our research assistant, Rebecca. It is unclear if having two co-researchers with CF (RD) co-facilitating as opposed to one, changed the dynamics of the group or content of findings. Co-researchers in focus groups one through three introduced themselves in the icebreaker exercise, "share something about yourself with the group," thematically and with disparate "levels of depth." For example, many in focus group one "kept it light" and shared information about their love of animals, personal hobbies and half were self-described "homebodies." Co-researchers in focus group two "got right to it" and contributed their age and circumstance of diagnosis, as well as the fact that some had had double lung transplants or had been on the transplant list. Co-researchers in focus group three "shared a mix, a bit about their careers and hobbies and aspirations." This may have been due to the difference in comfort levels of co-researchers at the

outset of focus groups or to group two "being older and having lived alongside CF for longer" therefore being more forthright from the beginning.

8.2.2 Socio-Demographic Details

At the time of this study, the age range for focus group one had been 19-29 with a mean age of 24.5, 39-47 for focus group two with a mean age of 42, and 24-30 for focus group three with a mean age of 28. Five co-researchers in focus group one identify as female and one as "lady boy." The gender of co-researchers in focus groups two and three are mostly female, however, there are two males in each group. The gender composition of the three groups means that the findings are rich with the perspectives of persons from fully three gender identities: female, male, and transgender. Age of CF diagnosis varied across focus groups with co-researchers in groups one and three mirroring the typical ratio of early to late diagnosis, at least 75% to 25% (83% to 17% and 86% to 14%, respectively). Focus group two differed in that three (of the co-researchers who remained) had been diagnosed late and two had been diagnosed early, prior to two years of age. This equals a ratio of 66% late diagnosis to 44% early diagnosis, which is unusual. Interestingly, the two co-researchers who had been diagnosed early had required double lung transplants, and those diagnosed later had milder disease symptoms, particularly those diagnosed in adulthood. This is reflective of clinical findings which show that persons with early diagnosis typically have more severe symptoms than that of their late diagnosis counterparts (Cystic Fibrosis Canada n.d; Cystic Fibrosis Foundation, n.d). The significance of this subject to findings in focus group two can be found throughout and particularly in the super-ordinate theme 1.c Experience living with CF (RD) day-to-day - early and late diagnosis. In terms of primary languages, co-researchers in focus group one were evenly divided with three citing English and three citing English/French or "English some French, Arabic and Hebrew." Co-researchers in focus group two

cited principally English as their primary language with one citing English/French and another identifying as principally French speaking. Co-researchers in focus group three cited principally English/French as their primary language(s) with three citing unilingual English. The significance of primary language(s) to findings includes the requirement of an interpreter for focus group one. The latter appeared virtually whilst our co-researcher communicated with her by phone. This may have impacted the quality of communication and possibly the group dynamic. One co-researcher in focus group two was principally French speaking and did not request an interpreter. She remained "slightly self-conscious," however, admittedly this did subside somewhat. Regarding place of residence co-researchers mostly resided in and around the greater Ottawa area which is consistent with the catchment area of The Ottawa Hospital Outpatient Adult Cystic Fibrosis Clinic. In terms of living and relationship status, most co-researchers across groups, fully 78%, lived with partners or spouses with two living with parents and two living independently. Of those living with parents or independently two cited being single and one divorced. Those who were single or divorced were evenly distributed across groups, one per group. This socio-demographic detail is significant because it sheds light on the reality that those with CF (RD) do live in partnered relationships and runs counter to common myths and misconceptions about living with CF (Cystic Fibrosis Foundation n.d.). Findings are replete with detailed descriptions regarding the impact of CF (RD) on relationships and specifically super-ordinate theme 1.b Experience living with CF(RD) day-to-day -interpersonal relationships. Employment status has already been discussed in this section in relation to focus groups one and three. It is worth noting here that all co-researchers in focus group two cited working or going to school full-time, although Arianna also marked ODSP on her socio -demographic questionnaire. This distinguishes focus group two as being the highest functioning in the study as it relates to employment, which may be explained by several

factors: the majority of co-researchers had a late diagnosis and for some time a milder form of CF; co-researchers are highly educated with two having a college diploma and three a university degree, two at the graduate level; co-researchers struggled with concealment versus disclosure of their illness and prioritized productivity over health in some instances, choosing to be identified as having CF (RD) so long as it did not indicate vulnerability or a "less than" totalizing identity; and some co-researchers have been resolute in becoming "good productive members of society." These factors are expounded upon in super-ordinate themes 3.b CF (RD) as a non-visible illness/disability - concealment vs disclosure (treatments and identity), and 5. CF (RD) positive aspects and meaning and purpose in life amongst others. In terms of the education of co-researchers in focus groups one and three, there seemed to be a "mix" of backgrounds. Across these groups fully four had completed high school/courses in high school or "other," three had completed college and six had completed university, two at the graduate level. The relevance to findings, according to one co-facilitator, "may be that the even mix of educational backgrounds in these groups contributed to some interesting exchanges."

Finally, in terms of the last two questions on the socio-demographic questionnaire - do you identify as a person with a non-visible illness/disability? Do you have previous experience as a client/patient in counselling and psychotherapy? – Answers were overwhelmingly affirmative. Only one co-researcher in focus group one answered yes/no to identifying as someone with a nonvisible illness/disability which she attributed to COVID making her symptoms more conspicuous. Two co-researchers in focus group three had similar responses to one another. One co-researcher answered, "illness yes but disability no" and another, "I have cystic fibrosis, which is a disability, but I don't let it stop me from doing whatever I want. Also, it's not apparent on the physical side." The latter two responses are consistent with the struggles of co-researchers Kallie

and Michael, to integrate CF as identity. The super-ordinate theme 4. CF and sense of self/identity details their sentiments on this matter. Only one co-researcher per focus group cited "no" to previous experience in counselling/psychotherapy although, upon further reflection, each had partaken albeit for only a few sessions. The fact that all co-researchers in this study had experience in counselling/psychotherapy, some since childhood, lends credibility to the framework that they developed, based in their experience-based knowledge.

8.2.3 Group Dynamics

Across all focus groups there were two notable group dynamics, with the first common to all three: the sense of community that developed amongst co-researchers, which this researcher elaborates upon in super-ordinate theme 8.b. Feedback and suggestions re: PAR methodology - fostering a sense of community. In terms of the second, a cursory glance at the dynamics of groups one through three might have one think that they are dissimilar, however, this is not the case, there is a common thread throughout. What all focus groups have in common, what co-researchers are collectively bringing in, is isolation from like others and a need to be heard, to be validated – in Arianna's case, to be validated for her preferred identity. In all instances, co -researchers strive to feel connected, although some are more gifted than others at building alliances and achieving this objective. Co- researchers feed off one another and at times their dynamic changes the trajectory of the group. It is imperative that we understand the dynamics of each group as this is a window into individual and collective needs and provides context to fully understand findings.

In focus group one, the second group dynamic is the following: whilst co-researchers mostly moved through the group developmental stages well, they many times got stuck overtly at storming (the group encounters difficulties). Sage's responses are replete with "shocking statements," for example, "I drink on a lot of sugary stuff and I don't take my insulin. Even after

taking things with sugar … And sometimes I don't eat the whole day." While likely a cry for help – "hear my pain"- her statements are increasingly dire as she fails to get the validation she requires. In focus group two, the second group dynamic involves two interconnected existential themes: individual identity and truth (Sbarby et al., 2019). Arianna's positive CF identity and her understanding of truth as literal differed with others' less favourable CF (RD) identities and their perception of truth as subjective phenomenon. Arianna's exchanges were littered with disagreeing statements such as, "so I was literally the polar opposite of Jake." Her needs seem more ambiguous than Sage's at first, however, she is likely struggling with existential anxiety and a complex relationship with CF as disability (Lingsom, 2008; Stone, 1995). What she requires is validation for her preferred identity but what she receives is the indignation of co-researchers who take exception to her "expert" stance and refuse to embellish upon her answers. Focus group two was also stuck at the storming stage of group development, albeit more covertly, many times. In focus group three, the second group dynamic is the following: 2) the seamlessness with which group three moved through the five stages of group development. Exchanges were supportive, for example, "That's a really good recommendation. Thanks for sharing…. One thing that I really related on is." Co-researchers shared early on that this was their first experience interacting with others with CF, which had been disheartening, and what they needed and received was a synergistic environment as a counterpoint to their social isolation. They moved through all stages of group development seamlessly and the likely difference in group dynamics from focus groups one and two was their ability to communicate their needs effectively which achieved the required result.

8.2.4 Super-ordinate Themes

- 1. Experience living with CF (RD) day to day;

- 2. Psychological impact of CF (RD);
- 3. CF (RD) as a non-visible illness/disability;
- 4. CF (RD) and sense of self/identity;
- 5. CF (RD) positive aspects and meaning and purpose in life;
- 6. Observations and recommendations;
- 7. Counselling and psychotherapy experiences;
- 8. Feedback and suggestions re: PAR methodology.

The eight super-ordinate themes in this study are consistent across focus groups, however, there may be variability between groups in terms of subsets. Again, subsets encapsulate and further pull together related emergent themes and reflect the preferred topic areas of the group. Subset titles are largely based on the language of co-researchers to accurately reflect their phenomenological experience. They demonstrate the nuance made possible by IPA. Where there is a super-ordinate theme and no subset this indicates that there had been no further unifying idea in the discourse. In the following pages this researcher shall compare focus groups where they have super-ordinate themes and/or subsets in common and in some instances, where there are unique super-ordinate themes and subsets between groups, for example, super-ordinate theme 3. CF (RD) as a non-visible illness/disability. Where there are unique but unrelated super-ordinate themes and subsets this researcher shall briefly summarize them and their relevance to each group. The aim here is to bring in comparison, a new perspective on findings. Emergent themes will appear either before or after quotes in parentheses.

1. Experience Living with CF(RD) Day-to-Day. The first super-ordinate theme, "Experience living with CF (RD) day to day," has nine subsets some consistently and others variously across groups. The distribution across focus groups is as follows:

Focus Group One. 1. a Symptoms and treatments; 1. b Interpersonal relationships; and 1.g CF and the impact of COVID;

Focus Group Two. 1. a Symptoms and treatments; 1. b Interpersonal relationships; 1.c Early and late diagnosis; 1.d Impact on career; 1.h Trikafta (this magic pill); and 1.i CF camp;

Focus Group Three. 1.a Symptoms and treatments; 1.b Interpersonal relationships; 1.e CF as spectrum; 1.f CF can be a dark disease; and 1.g CF and the impact of COVID.

1.a Experience Living with CF(RD) Day-to-Day - Symptoms and Treatments. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Experience living with CF(RD) day-to-day - symptoms and treatments, co-researchers struggle with CF plus other conditions such as CFRD (group one) and lung transplantation and CFRD (group two). Still, the similarity between their experiences seems apparent. All co-researchers must deal with the existential concern of the uncertainty of life in the context of living with a chronic illness. CF(RD) is a fluctuating illness with encumbering symptoms and time-consuming treatments. One's health could decline precipitously and does so inevitably with advancing age. Sometimes CF(RD) requires making pivotal life changes, for example, becoming a "homebody" or a "recluse" or curtailing employment. Motivation for treatments wavers and this requires psychological adjustment, time management and, in the instance of group three, humour. Co-researchers in focus group one (CFRD) overall report more time spent on treatments, however, examples of spending two hours or more on treatments can be found individually among co-researchers across groups.

Most co-researchers in focus group one not only struggle with CF but also CFRD and other ailments. Their symptoms can include "fatigue" and "exhaustion" and their treatments are geared not only to lung clearance but also blood sugar monitoring and insulin injections. This can feel

like a "burden" and cause one to become a "homebody" (1, 2, 3). Some choose to go back to school or, like Karina, remain at home "because it's just too hard" to work and "maintain [one's] health at the same time" (4, 5). Sometimes CF (RD) can "throw you a curveball," so that you think that you have a handle on it but then you don't, which is not easy (6). A life with CF (RD) can include exacerbations, protracted periods on medications, erratic sometimes debilitating symptoms and hospitalizations. Some "stop taking care of themselves as a whole," even temporarily, due to the onerousness of treatments (7). Co-researchers in focus group two speak to their disparate experience of CF (RD) when young in terms of how it impacted their day to day functioning and the time spent on treatments, with some having had more debilitating effects than others (8). Still the commonalities amongst them include the inevitability of one's health declining, for example, reduced stamina, increased symptoms, and longer treatment time which can include, in Arianna's case, becoming a "recluse" (9, 10). All agree that CF (RD) can be "sneaky" with health deteriorating with no apparent notice and beyond one's control (11, 12). Co-researchers in focus group three centre their discussions on CF symptoms and treatments around the deterioration that one feels as one ages, how their lives are different from "normal folk" and how difficult it is to remain motivated for treatments (13, 14, 15). They share their struggles with treatment adherence which includes time management and allowing for imperfection (16, 17, 18, 19, 20). They have a lively exchange at the end of group which gives a rare insight into their onerous treatment regimens and shared sense of humour.

1.b Experience Living with CF(RD) Day-to-Day - Interpersonal Relationships. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Experience living with CF(RD) day-to-day - interpersonal relationships, co-researchers share their experiences relating to strangers, friends, and family, and with intimate partners, all while living

with a non-visible and life-limiting illness/disability. Group one differs only in that there is primarily a focus on friends and family rather than on intimate relationships. This may result from the relatively young age of the group. More generally, existential concerns such as loneliness, social isolation and existential isolation can arise due to misconceptions, the capriciousness of CF (RD) and concealing the extent of one's symptoms so as not to worry others (van Bruggen et al., 2017). Alternatively, one might form meaningful connections and strong bonds due to the circumstances of one's illness. In dating, one may confront life's expectations, for example, starting a family or finding someone who will stick by you despite your illness. Once in a committed relationship, existential conversations may be had regarding the intimacies of life and death.

Co-researchers in focus group one discuss the impact of CF(RD) principally on their familial relationships or on friendships. There is a feeling of "loneliness" and lack of "meaningful connection" that comes with CF(RD) due to losing friends to the illness, frequent exacerbations and hospitalizations which interfere with being consistently present. One co-researcher, Sage, laments about having "no boyfriend who would accept me" once they realize that she is a "sick person" (21, 22). Conversely, several co-researchers speak to developing strong bonds with a small circle of family and friends whom "you really trust and that understand" (23, 24). Some co-researchers in focus group two conceal the extent of their illness from family, including a spouse, to circumvent worry, which can negatively impact authentic connection (25, 26). Two co-researchers, Kyle and Jake, talk about the difficulty of dating due to not "feeling ready or mature enough" to manage expectations or finding a partner who will "stick by you" which delayed intimacy (27, 28, 29, 30). Arianna and Kyle speak to the imperative of having existential conversations with partners, for example, the prospect of having to move on without them or one's coughing triggering traumatic memories and the prospect of death (31, 32). Co-researchers in focus

group three discuss CF and the impact on their interpersonal relationships beginning with misperceptions on the social level and concluding with "difficult conversations" with intimate partners. Co-researchers have differing reactions to misperceptions, with Jill, for example, internalizing other's "preconceived notions" regarding CF and thin bodies and Charlene choosing to be "transparent" and "educate" regarding her symptoms (33, 34). Regarding close relationships with friends and family, Jay, Karen and Khris speak to hiding their true state of health which results in "dying inside," "crashing on the couch," or "crying [oneself] to sleep" (35, 36, 37, 38). Jay, Karen and Khris subjugate their own needs for that of others and suffer a personal and existential cost – loneliness and social isolation. Karen finally breaks free of her previous patterns and decides, like Charlene, to be more transparent "allowing for vulnerable conversations" and finding "community in that" (39). Once co-researchers find life partners, like those in focus group two, they must have "difficult conversations," from sexual intimacy to fertility to "preparing your partner to bury you" (40, 41, 42, 43). One co-researcher, Kallie, shares that she has finally found an understanding and supportive partner after a history with "shitty men," one of whom stated, "why would I pursue a future with you if you have such a low life expectancy?" This is likely challenging for Kallie not only personally but on an existential level, having been confronted with her own finitude by someone else (44).

1.g Experience Living with CF(RD) Day-to-Day - CF(RD) and the Impact of COVID. Regarding focus groups one and three and the common super-ordinate theme and subset: Experience living with CF(RD) day-to-day - CF(RD) and the impact of COVID, co-researchers in both groups highlight the following: people conflate CF and COVID; few fully understand their increased risk of infection; COVID has made the non-visible visible; all of these factors in addition to working from home has exacerbated fear, loneliness, mental health issues, and a sense of

meaninglessness. On an existential level, COVID may be a constant reminder of illness, physical vulnerability and finitude; positive aspects to COVID include more time for treatments, making pivotal career changes and realizing that one can in fact cope.

Co-researchers in focus group one outline both the negative and positive impact of CF(RD) and COVID. Regarding the negative implications of COVID: co-researchers worry about contracting the virus which exacerbates their fear of interacting with others; mandatory isolation causes one co-researcher to lose friends who don't understand her degree of caution; people misconstrue coughing for COVID; working from home makes the "pressing matter" of finding employment with benefits more difficult; and one co-researcher, Karina, is turned away from a much-anticipated fertility clinic appointment because she is told she is at high risk for infection (45). All these factors have an impact on mental health, with some feeling stressed and more isolated than usual. Regarding the positive implications of COVID: one co-researcher shares that finally having time for treatments is "not a bad thing;" another has taken the opportunity to go back to school; and three co-researchers endorse being "healthier" than ever because they are less exposed to germs (46, 47, 48). Co-researchers in focus group three also highlight both the negative and positive impact of CF and COVID. To begin, Khris and Karen poke fun at "regular people" having a difficult time adjusting, utilizing metaphor, "welcome to the dark side" (49). Regarding the negative implications of COVID: people mistake CF for COVID; there is a "mixed response" to their need for increased precautions; they must ask themselves "is this worth it" before leaving the house; and working from home has negatively impacted mental health with Michael feeling "depressed and lonely" and Jill losing motivation for treatments. Here, Jill also expresses the existential concern of meaninglessness, "what's the point anymore?" (50, 51, 52, 53, 54, 55, 56, 57). Regarding the positive implications of COVID, Kallie and Charlene respectively find more

time for treatments and the recognition that one can "adapt" having coped with the anxieties of living with CF (58).

1. Experience Living with CF(RD) Day-to-Day - 1. c Early and Late Diagnosis; 1.d Impact on Career; 1.h Trikafta (This Magic Pill); and 1.i CF Camp.

Unique to focus group two are subsets: 1.c early and late diagnosis; 1.d impact on career; 1.h Trikafta (this magic pill); and 1.i CF camp, which reflect the characteristics and foci of the group. For example, co-researchers in focus group two (CF 39 +) are older and have been diagnosed with an inverse ratio of early to late diagnosis, making that a topic of conversation. Most have had time to build careers and are passionate about contributing to society. At the same time, they have grown up in a different time and did not have access to the same treatments as the younger generation. The advent of Trikafta, with the promise of a better quality of life, felt like a miracle, albeit at the time of this study only available to few on compassionate grounds. Finally, CF camp was an anomaly, an experiment that had dire consequences. This too is reflective of the age of co-researchers as CF camp is prohibited today.

1. Experience Living with CF Day-to-Day – 1.e CF as Spectrum; **1.f CF can be a Dark Disease.** Unique to focus group three are subsets: 1.e CF as spectrum; and 1.f CF can be a dark disease. Co-researchers in focus group three (CF 18-30), whilst younger than focus group two, addressed the capriciousness of CF more than any other group and used the metaphor of it being a dark disease to make sense of their illness experience.

2. Psychological Impact of CF (RD). The second super-ordinate theme, "Psychological impact of CF (RD)," has three subsets, again some shared across groups and some idiosyncratic: 2.a Interrelationship of physical and mental health; 1.b Isolation from others with CF; and 1.c Not feeling good enough. Focus group one has two subsets, focus group two has three subsets, and

focus group three has two subsets. Focus groups one, two and three have the common subset: 2.b Isolation from others with CF. Focus groups one and three have the common subset: 2.a Interrelationship of physical and mental health. The distribution across focus group is as follows:

Focus Group One. 2.a Interrelationship of physical and mental health; and 2.b Isolation from others with CF;

Focus Group Two. 2.b Isolation from others with CF; and 2.c Not feeling good enough;

Focus Group Three. 2.a Interrelationship of physical and mental health; and 2.b Isolation from others with CF.

2.b Psychological impact of CF (RD) – isolation from others with CF. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Psychological impact of CF (RD) – isolation from others with CF, there are mostly commonalities and few differences. Their interpersonal isolation has a psychological impact and permeates conversation, with those in focus group three especially experiencing a temporary reprieve in their synergistic dynamic. PAR provides a counterpoint to the experience of not being connected with others who share your perspective. The benefits of engaging in a PAR focus group as a counterpoint to their collective isolation has been expressed by co-researchers across groups and will be expounded upon in super-ordinate theme 8.b Feedback and suggestions re: PAR methodology – fostering a sense of community.

Co-researchers in focus group one speak to the "unique and devastating" reality of having to remain apart, and to the alienation from those around you because they cannot possibly understand what it feels like to be in a CF (RD) body (59, 60). Amelie conversely raises a sentiment that likely is shared, although only Jake raises this in a post focus group interview, the need to keep one's distance from others with CF (RD) to protect oneself from loss (61). Co-researchers in

focus group two speak to being kept apart from others with CF (RD) which is "ridiculous" and counterproductive because, for one thing, they can learn "what works" from one another (62, 63). Arianna points out that even "cancer patients can get together." Being kept apart in high school from others with CF likely impacted Arianna's ability to integrate a realistic CF identity instead of being "the poster child for CF" (64). Co-researchers in focus group three talk about their isolation from one another in the icebreaker exercise, throughout group and when they are signing off. Khris and Jill have a similar experience to Arianna in that they were kept apart in high school, they were "searching for one another without success" (65). The collaboration that develops, their experience of finally engaging meaningfully with like others, allows for their collective unburdening (66, 67, 68).

2.a Psychological impact of CF (RD) – Interrelationship of Physical and Mental Health. Regarding focus groups one and three and the common super-ordinate theme and subset: Psychological impact of CF (RD) - interrelationship of physical and mental health, focus groups one and three agree to their cyclical connection, with group three creating the nomenclature, a unique "mental load." For both groups there exists the unequivocal reality that mental health impacts physical health which impacts mental health and so on. To seek counselling/psychotherapy support, the help that one needs, one must move past stigma, shame, denial, and trauma and prioritize one's mental health.

Co-researchers in focus group one underscore the reciprocal relationship between their physical and mental health, with Jasmine concluding, "either way it's damned." She elaborates by referring to this relationship as a "a double-edged sword," where her anxiety and depression can impact her motivation for treatment which can impact her physical health and so on (69, 70, 71). Amelie and Jasmine agree that feelings of stigma and shame result from being born with CF and

the expectation that you can "hold that on [your] shoulders." This might curtail seeking the counselling/psychotherapy support you need (72, 73). Finally, Karina refers to her dilemma of either beginning a lifesaving medication, Trikafta, or having a biological child which has both psychological and existential implications. In terms of psychological implications, she draws a connection between "too much stress [causing] lung infections." In terms of existential implications, her dilemma is quite an existential confrontation where life and death are playing an important role (74, 75, 76). Co- researchers in focus group three also maintain that physical and mental health are interconnected and refer to this as their unique "mental load." Having a "mental load" means many things including: deciding whether to take risks and curtail treatments which has implications for one's physical health; having to cope with "survivor looks" from family who see you as "the grandchild who's almost dying all the time;" one's mood "rising and falling" depending upon one's health situation; frequent hospitalizations which bring on worry that one might leave through the morgue; and "feeling less of a person" and being afraid that one's future will be taken away which can result in depression (77, 78, 79, 80, 81). Co-researchers cope by employing the following strategies: going into "survivor mode" or pushing through physically which can be "numbing emotionally;" putting on a "default public face" or "convincing themselves that they're fine;" and "[burying]" their trauma but finally conceding that "mental health in CF really do go together" (82, 83, 84, 85, 86, 87).

2.c Psychological Impact of CF (RD) - not feeling good enough. Unique to focus group two is subset 1.c not feeling good enough. This reflects the sentiment of most co-researchers who separately felt in relation to CF (RD) that they were a burden, inferior, bothering people, and "not good enough." Even Arianna, who had been the "poster child for CF in Ottawa" growing up felt survivor's guilt at having had a lung transplant (88, 89). The consequence of "not feeling good

enough" meant that co-researchers in focus group three often felt compelled to conceal their illness or at least the perception of vulnerability.

3. CF(RD) as a Non-visible Illness/Disability. The third super-ordinate theme, "CF(RD) as a non-visible illness/disability," has three subsets, one unique to each group: 3.a Walking the line between sick and not sick; 3.b Concealment vs. disclosure (treatments and identity); and 3.c The ignorance of people. The distribution across focus group is as follows:

Focus Group One. 3.a Walking the line between sick and not sick;

Focus Group Two. 3.b Concealment vs. disclosure (treatments and identity);

Focus Group Three. 3.c The ignorance of people.

There are many commonalities in the responses of co-researchers to super-ordinate theme CF(RD) as a non-visible illness/disability, across the three subsets: 3.a Walking the line between sick and not sick; 3.b Concealment vs. disclosure (treatments and identity); and 3.c The ignorance of people. The most central is that they experience existential isolation, there is an incongruence between their internal and external worlds (van Bruggen et al., 2017). Misconceptions at best and overt cruelty at worst abound, and no one wants to be defined by CF (RD) particularly if this means that they appear less able. The existential concepts of Eigenwelt and Mitwelt are relevant here, there is a misalignment between the psychological and social dimensions (Marseille & Messias, 2020). The dilemma of concealment versus disclosure exemplifies this conflict. Do I honour my true self or attempt to fit in? This has implications for both mental and physical health. Having a non-visible illness/disability holds an existential responsibility, they have a choice regarding how they present themselves to the world and most have decided on discernment depending on the context. Only co-researchers in focus group two collectively decide that disclosure is preferable to promote understanding. Where they differ is in emphasis. Again, employing the concepts of

Eigenwelt and Mitwelt is useful here (Marseille & Messias, 2020). Co-researchers in focus groups one through three all hover in the psychological dimension, however, focus groups one and three refer more to feelings, as example, "denial," "aggression" and "shame," whilst co-researchers in focus group two concentrate on CF (RD) as it relates to identity (90, 91, 92, 93, 94). Lastly, whilst co-researchers in focus groups one through three all touch on CF (RD) in the social dimension, those in focus groups one and two refer mostly to misperceptions and focus group three speak to mistreatments – "the ignorance of people." Upon further analysis, it may be that this disparity has less to do with the quality of their encounters and more to do with the relative comfort of co-researchers in focus group three in sharing their discomposure with one another (95, 96, 97, 98, 99, 100).

3.a CF(RD) as a Non-visible Illness/Disability - Walking a Line Between Sick and not Sick. Unique to focus group one is subset 3.a walking a line between sick and not sick, a term created by Alice and corroborated by Jasmine (101). Here, co-researchers discuss the problem of "not looking sick but feeling sick" or feeling well relative to others on the spectrum of CF (RD) but still not quite "normal" (102). They ponder the following questions: How does one walk that line between sick and not sick? When one's illness/disability is non-visible, and symptoms are fluctuating how does one represent oneself to the world? Under what circumstances do you decide to disclose your illness/disability or keep it concealed? Co-researchers struggle in non-intimate relationships where misunderstandings are common and in close relationships where they may feel unseen. Emotional implications can include feeling rejected and having difficulty validating one's own experience. Still, having a non-visible illness/disability has its advantages. When symptoms are less overt one can choose when to disclose one's illness thereby avoiding being judged by others.

3.b CF(RD) as a Non-visible Illness/Disability - Concealment vs. Disclosure (Treatments and Identity). Unique to focus group two is subset 3.b Concealment vs. Disclosure (treatments and identity). In this instance, co-researchers underscore the dilemma of concealment versus disclosure in the realm of treatments and identity. In the realm of treatments, particularly in the public sphere, should they disclose their treatment regimen they may be met with castigation, health-related stigma, or an unsympathetic response. Conversely, should they conceal and/or avoid their treatments this too comes at a personal cost, their health may be negatively impacted. Co-researchers also face the dilemma of concealment versus disclosure in the realm of identity. Most but not all conceal their illness because they do not want their identity to be synonymous with CF (RD), "it's not something I am" (103, 104). Still, at this point most co-researchers have decided that disclosure is "not necessarily a bad thing" since this may "normalize" CF (RD), promote understanding and compassion and secure much needed accommodations (105, 106, 107).

3.c CF as a Non-visible Illness/Disability - the Ignorance of People. Unique to focus group three is subset 3.c The ignorance of people. Here, co-researchers focus on "the ignorance of people," a phrase created by Khris, which underscores the detrimental reactions of others to CF (108). Misconceptions, judgement, and disbelief are common, even when one is most vulnerable, as example, in the instance of neurosurgery. This results in experiencing a myriad of emotions, including feeling unseen, "shame," "frustration," "aggression" and "having to prove that you have CF or how sick you are" (109, 110). Even when well-meaning, people can be misguided and undermine one's autonomy or disclose one's illness without one's consent. Finally, some distinguish between having a non-visible illness/disability versus a visible illness/disability, preferring the former because one can control when to hide it and in what context, for example, dating. When CF is visible, and people have unfavourable reactions one co-researcher, Khris,

perhaps in an act of defiance, decides to embrace her body as "beautifully strange." Subconsciously this may be her way of coping with her existential isolation, reconciling her inner and outer worlds (111, 112).

4. CF(RD) and Sense of Self/Identity. The commonality amongst co-researchers in focus groups one through three centres on their personal evolution in terms of CF (RD) and sense of self/identity. Eventually, all must integrate the reality that they have a capricious and life limiting illness. This takes tenacity, honesty with oneself and, in some instances, finding peace with one's finality. All would likely agree with the statements of Khris and Jay, that they are divided between two worlds, "too healthy to be in the sick world … too sick to be in the healthy world" and "in between disabled and able" (113, 114). As they journey, no one wants to be "put in a box" or identified with CF (RD) as their sole identity particularly if this is associated with weakness (115). The dissimilarities amongst co- researchers in focus groups one through three are few. There is a difference in emphasis. Focus group one calls attention to their CF (RD) experience versus "normies," focus group two to others having a nuanced account of their identities and focus group three to their gradual acceptance of CF as their health declines and they age.

Co-researchers in focus group one struggle with their sense of self/identity because their illness/disability is non – visible and therefore how they look on the outside does not reflect how they feel on the inside. They distinguish between themselves and "normies" or people who do not have CF(RD), which can be isolating or conversely consolidating of a CF identity (116). One co-researcher, Jasmine, describes learning to finally accept CF as she has grown through its many challenges. Most co-researchers in focus group two, even Arianna, did not want to be defined by CF if it signified limited abilities. Much discussion centred on others, including counsellors/psychotherapists and interdisciplinary team members, understanding that they have

nuanced identities and that they are persons first over and above their illness. Finally, many agreed that one's upbringing plays a significant role in one's sense of self/identity in relation to CF (RD). Co-researchers in focus group three were at different stages regarding CF, sense of self and identity. Where they sit in terms of acceptance of CF reflects the study of Horky et al. (2017) who found that CF played more of a role in the identities of older and sicker adolescents. Kallie and Michael "are not there yet" in terms of their acceptance of a CF identity, however, they concede that this has evolved with age (117, 118). Finally, Charlene talks about the acceptance of death being integral to her acceptance of CF. This may speak to her coming to terms with some of the existential distress inherent in having a life limiting illness (Trandel et al., 2019).

5. CF(RD) Positive Aspects and Meaning and Purpose in Life. Co-researchers across focus groups one, two and three speak to their positive experiences and meaning and purpose in life because of the hardships of living with CF(RD). They call to mind Frankl's three core principles - freedom of will, will to meaning, and meaning in life. In the face of CF (RD), they have discovered positive attributes and have a shared drive to find meaning and purpose in life. They persevere despite hardship, focus on what matters, and find what is uniquely meaningful to them (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Frankl et al., 2010). As example, co- researchers in focus group one "matured a lot quicker," "learned to stand up for themselves," and found "meaningful connections" (119, 120, 121). As well, living with capricious health has given them the perspective to "appreciate the moment" rather than focus on drama (122). When focusing specifically on meaning and purpose in life, co-researchers attempt to find a career that fits within one's lifetime, with one's health situation or, alternatively, a purpose apart from employment. Co-researchers in focus group two struggle with CF (RD) but it also has helped them to focus on what matters, to "not take anything for granted," and to "live life full" (123, 124, 125).

Two co-researchers, Jake, and Marie, speak about CF (RD) compelling them to "contribute to society" (126, 127, 128, 129). Finally, Arianna has found purpose in "educating parents" to not be afraid of CF, to allow their kids to thrive (130, 131). Co-researchers in focus group three, like those in focus groups one and two, are absent the "arrogance of health" and this has compelled them to find perspective, to focus on the people and things that are "worth it" and "bring joy" (132, 133, 134, 135). Setting "reasonable" goals is important and can be "a constant existential thing" given that there is the new reality of aging (136, 137, 138). Two co-researchers, Khris and Karen, speak to CF fostering their sense of empathy (139, 140). Finally, Jay and Khris would have liked to find meaning and purpose in alignment with society's expectations, but bemoan falling short regarding gender roles and fertility, "here's this on a platter … deal with that" (141).

6. Observations and Recommendations. The sixth super-ordinate theme, "Observations and recommendations," has three subsets: 6.a CF(RD) counsellors/ psychotherapists - attitudes, knowledge, and skills; 6.b CF(RD) doctors, nurses and all allied health; and 6.c Healthcare system. Focus groups one and two have two subsets and focus group three has three subsets. Focus groups one, two and three have the common subsets: 6.a CF(RD) counsellors/ psychotherapists-attitudes, knowledge, and skills; and 6.b CF(RD) doctors, nurses, and all allied health. Focus group three has the unique subset: 6.c Healthcare system. The distribution across focus group is as follows:

Focus Group One. 6.a CF(RD) counsellors/ psychotherapists-attitudes, knowledge and skills; and 6.b CF(RD) doctors, nurses and all allied health;

Focus Group Two. 6.a CF(RD) counsellors/ psychotherapists-attitudes, knowledge and skills; and 6.b CF(RD) doctors, nurses and all allied health;

Focus Group Three. 6.a CF counsellors/ psychotherapists-attitudes, knowledge, and skills; 6.b CF doctors, nurses and all allied health; and 6.c Healthcare system.

6.a Observations and Recommendations - CF(RD) Counsellors/ Psychotherapists-Attitudes, Knowledge, and Skills -Attitude. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Observations and recommendations - CF(RD) counsellors/ psychotherapists-attitudes, knowledge, and skills, similarities regarding recommended attitudes include: "non-judgement" and "empathy" as a counterpoint to CF clinic appointments where some have felt judged by doctors; other attitudes centred on creating an atmosphere of trust conducive to "opening up," for example, being friendly, being a "good listener," "validating" patient experience, being the right amount of walking beside without being "too nosy," being "down to earth," having a sense of humour, being "cooperative," having a non-expert stance, and being an "ally" which includes remaining steadfast even when things get "tough" and being able to "differentiate [the person] from the disease." The latter is an important statement regarding identity as an existential given (van Bruggen et al., 2017); being appropriately self-disclosing or transparent; and attitudes such as having a "thick skin" or being confrontational where needed.

Co-researchers in focus group one highlight the importance of "nonjudgement" and "open-mindedness" as necessary precursors to "opening up" and as a counterpoint to CF clinic appointments where some have felt "judged by doctors" (142, 143, 144). Other attitudes that are important on the part of a counsellor/psychotherapist are being friendly, appropriately self-disclosing, a "good listener," expressing empathy and "validating" co-researchers' experiences (145, 146, 147). Co- researchers in focus group two also find non-judgement crucial to talk openly and engage in the process of therapy (148). Empathy is similarly mentioned as an important attitude as are letting patients know "I'm here if you need me" without being too "nosy," "compassion," being "down to earth" and "humour" (149, 150, 151, 152, 153). Co- researchers in

focus group three likewise extoll empathy on the part of their counsellor/psychotherapist as a counterpoint to the judgement they receive at CF clinic appointments or by "doctors and residents who are stone cold" (154). Another important attribute is having "thick skin" because "sometimes you want to blame somebody" or you "don't want them to be put off by your dark humour" (155, 156, 157). One co-researcher, Michael, shares that, while empathy is important, he also requires his counsellor/psychotherapist to confront him when he is being "too dark on the devil part" (158). Fully four co-researchers refer to the counsellor/psychotherapist being an "ally" which is essential to "establishing trust" (159, 160). Being an "ally" entails "standing beside [us] when things get tough," and "looking at [us] as not just a disease … but as a real human" with problems outside the purview of CF. (161, 162, 163, 164). Other important attitudes include being appropriately transparent, an attribute also mentioned by co-researchers in focus group one, being "cooperative," acknowledging that "you're not an expert in my experience of chronic illness" and ensuring that patient's needs are addressed expeditiously (165, 166, 167, 168).

6.a Observations and Recommendations - CF(RD) Counsellors/ Psychotherapists- Attitudes, Knowledge, and Skills -Knowledge. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Observations and recommendations - CF(RD) counsellors/ psychotherapists - attitudes, knowledge, and skills, similarities regarding recommended knowledge include: a thorough understanding of chronic illness or CF (RD), preferably based in practice experience; knowledge regarding the "day-to-day struggles" and long-term implications of CF (RD), for example, typical medications and health complications, and the understanding that CF (RD) is a spectrum and progressive; one must be informed regarding the mental health implications of CF (RD); it might be helpful to understand certain attitudes of those with CF (RD) regarding their mental health, for example, they may struggle with the "burden

complex" or not wanting to reach out for help; other necessary understandings include seeing those with CF (RD) as "persons first" and as experts in their own experience, which has important practice implications, respectively, the therapist not solely focusing on CF (RD) and "being willing to turn over the reins." The latter point is reminiscent of existential psychotherapies such as logotherapy or the work of van Deurzen (2012) where "as a first rule of thumb, clients should always be allowed to take the lead in how far they wish to go with their own explorations" (Frankl, 1967; van Deurzen, 2012, p.3; Yalom, 1980, 2002).

Co-researchers in focus group one speak to the importance of counsellors/psychotherapists having comprehensive knowledge of chronic illness. They also must understand the complexities that come with CF (RD) such as the fact that it is a degenerative illness and has mental health implications, for example, "grief, depression, anxiety" and "denial" (169, 170, 171, 172). One co-researcher, Amelie, also thinks it important to understand the "day to day struggles" of persons with CF (RD) which "might not be just quite so simple" (173). Co-researchers in focus group two want counsellors/psychotherapists to have "excellent knowledge of CF" based on working with persons so afflicted. They should also understand the challenges that persons with CF (RD) face, for example, the progression of the illness, the transplant experience, medications, and relevant resources (174, 175, 176, 177, 178, 179, 180, 181). It is imperative to see those with CF (RD) as "persons first" who may not want to solely focus on CF (RD) when they reach out for help (182, 183). Co-researchers in focus group three want counsellors/psychotherapists to "know more about CF not what Wikipedia tells them." This includes understanding that "CF is a spectrum," being knowledgeable regarding "mental health and CF" and specific "health related issues … and relevant resources." It might be helpful, according to one, to even "have a passion for CF" (184, 185, 186, 187, 188). Counsellors/psychotherapists should know that many with CF experience the

"burden complex" and should not make the assumption that "because [those with CF seem] healthy physically [they're] healthy emotionally" (189, 190, 191). Finally, it is important to understand that persons with CF are open to learning about their illness, but that they are "experts" in their own experience and "be willing to turn over the reins" (192, 193).

6.a Observations and Recommendations - CF(RD) Counsellors/ Psychotherapists-Attitudes, Knowledge, and Skills - Skills. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Observations and recommendations - CF(RD) counsellors/ psychotherapists-attitudes, knowledge, and skills, similarities regarding recommended skills include: meeting patients where they are at allowing for "hard emotions" and the "dark" "uncomfortable" side of CF (RD); employing an "individualized approach" that appreciates different personality types and coping styles as well as recognizes the knowledge base and preferred approaches of patients; asking the right questions where it is difficult to put feelings and thoughts into words; judiciously moving patients in the direction of positive change – by teaching techniques to cope, pointing out progress and behavioral patterns, piercing through "I'm fine as a default" or helping to "face fears;" and providing relevant resources to reinforce and consolidate learning. Whilst co-researchers across focus groups had productive discussions regarding important counsellor/psychotherapist skills, those in focus group three were the most prolific. A review of the socio-demographic details of co-researchers across focus groups shows that those in focus group three had spent the longest duration in therapy. This may account for the disparity.

Co-researchers in focus group one consider the following skills essential for counsellors/psychotherapists working with those with CF (RD): empathy or starting where the client is at, which means not forcing positivity but sometimes being with them in "dark places;"

asking them the right questions to put their thoughts/feelings into words and "leave in the direction of progress;" utilizing an "individualized approach" tailored to each client's personality type or coping style to help them feel "nudged" and "supported"; creating a safe space to allow for clients to sit with their "hard emotions" and realize they are not "scary" (194, 195, 196, 197, 198). One co-researcher, Amelie, also thinks that helping parents to cope and being able to profer a mental health diagnosis (if within one's scope of practice) are also important skills (199, 200). Co-researchers in focus group two highlight the importance of these counsellor/psychotherapist skills: offering mindfulness exercises which are "relatable" at the outset of sessions to help with grounding; teaching techniques to cope, pointing out progress and patterns of behaviour and offering relevant resources to reinforce learning; and utilizing creative approaches, for example, journaling, that resonate more than "old fashioned therapies" (201, 202, 203, 204, 205). Co-researchers in focus group three at first speak more generally about counsellor/psychotherapist skills. The common theme is not wanting to be "talked at" about banalities but "talked with" about things that matter, including the uncomfortable side of CF. Each co-researcher suggests skills for counsellors/psychotherapists based on what is meaningful to them: piercing through "I'm fine as a default" and getting to the root of the overall problem; talking "to me not at me" regarding the "gross and uncomfortable" side of CF even if I push you away; moving beyond "just … listening and empathy" to having a "structured approach" and helping to "face things you fear or were afraid of;" moving beyond "the hero complex where people feel the need to like with people with disabilities … you're an inspiration" and instead having boundaries as an ongoing conversation and pushing where necessary to talk about the "dark stuff;" "having a personalized approach" which includes knowing that persons with CF are a "fairly knowledgeable group about what is affecting us;" moving beyond "predetermined questions" and talking about things that matter, for

example, relationship difficulties or CF (206, 207, 208, 209, 210, 211, 212, 213, 214, 215, 216). When co-researchers speak to more specific counsellor/psychotherapist skills these include everything from "being able to read body language" to "remembering the microdetails" and "providing one strategy to hold onto." Most specific skills are suggested by Karen and can be summarized by her statement, "I need a counsellor who's willing to walk with me, not yelling after them to catch up" (217, 218, 219, 220).

6.b Observations and Recommendations - CF(RD) Doctors, Nurses, and all Allied Health. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Observations and recommendations - CF(RD) doctors, nurses and all allied health, co-researchers seemingly have diverse recommendations, however, a shared perspective, that is counselling is a required service. Speaking from experience - based knowledge, counselling may be offered through social work/mental health or proffered by doctors who are attentive to them as persons apart from their illness and can help them to anticipate its progression. Co-researchers in focus group one recommend that there be more synergy between the interdisciplinary team and social work/mental health so that patients are made aware of this resource and referrals are extended when needed, for example, when they have had a "tough" CF clinic appointment (221, 222). One co-researcher, Amelie, also recommends that doctors treat patients "more as a person" than as "a medical case" when addressing the subject of mental health. The subtext is that mental health resources should not be "pushed" but made available and that opening up with a physician is more plausible when one is seen as a person beyond one's illness (223). In terms of focus group two, one co- researcher, Kyle, stresses the importance of doctors counselling CF patients regarding the "progression" of CF, that there are "commonalities," for example, a gradual decline in health. This will help them to "keep an eye out" and prepare for the future (224, 225). Another co-

researcher, Arianna, speaks to the importance of interdisciplinary team members coming in with a positive attitude and a "clean slate" because persons with CF are not "all the same," albeit "the most positive people you will ever meet" (226, 227). Here, Kyle finds it helpful when doctors point out the common progression of the disease whereas Arianna does not appreciate comparisons, "we're not all the same in any way, shape or form." The disparate perspectives of co-researchers in focus group two likely reflects their differing relationship with CF (RD) and sense of self/identity, with Arianna more resistant to accepting the limitations of her illness. Co-researchers in focus group three centre their discussions on three main concepts. Khris makes a similar point to Kyle in that she believes that "prepping" both patients and parents regarding what to expect, the decline of the aging body, would be helpful (228). Charlene brings in her example of being overlooked when not "super sick" but nonetheless in need of emotional support, which highlights the predicament of those with a non-visible illness/disability. She recommends that even when not overtly sick those with CF receive the help they require (229). Karen and others speak to the "dream sequence" for mental health services at CF clinic, offering both one to one counselling sessions and group therapy (230).

6.c Observations and Recommendations - Healthcare System. Unique to focus group three is the super-ordinate theme and subset: 6.c Observations and Recommendations - Healthcare system. Here co-researchers Charlene and Jay make the very important observation that the healthcare system is "not made to deal with chronic illness that can be acute sometimes." Whilst their locus of control when dealing with "the more systemic side of things" appears internal (advocacy) versus external (explanation), their message is congruent. They recommend collaboration, understanding and nuance in the delivery of much needed medications, health care benefits and services (231, 232, 233).

7. Counselling and Psychotherapy Experiences. The seventh super-ordinate theme, "Counselling and psychotherapy experiences," has two subsets: 7. a Helpful experiences; and 7. b Unhelpful experiences. Focus groups one and three have two subsets and focus group two has one subset. Focus groups one, two and three have the common subset: 7. a Helpful experiences. Focus groups one and three have the common subset: 7. b Unhelpful experiences. The distribution across focus group is as follows:

Focus Group One. 7. a Helpful experiences; and 7. b Unhelpful experiences;

Focus Group Two. 7. a Helpful experiences;

Focus Group Three. 7. a Helpful experiences; and 7. b Unhelpful experiences.

7.a Counselling and Psychotherapy Experiences – Helpful Experiences. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Counselling and psychotherapy experiences – helpful experiences, co-researchers across groups speak primarily to beneficial therapist skills – validation, listening and reciprocal dialogue among them – with only focus group one more explicitly speaking to the imperatives of empathy and trust. Notwithstanding, co-researchers across groups have the following in common in their accounts: being present with clients as a necessary condition to therapeutic engagement and change. Co-researchers in focus group one share their helpful experiences in counselling and psychotherapy which align with their observations and recommendations for CF(RD) counsellors/ psychotherapists – across all domains: attitude, knowledge, and skills. For example, co-researchers find it helpful when the therapist is empathetic, validating, creates an atmosphere of trust, and helps them to understand their thought process and sit with their difficult feelings, which makes these less "scary" (234, 235, 236, 237, 238). They also value being challenged and learning about relevant resources to consolidate learning (239). Many agree that it is empowering to realize that

one has carried over the skills learned in counselling/psychotherapy and that the trust developed allows for trusting relationships with others in their lives (240, 241). Co-researchers in focus group two speak less about the important attitudes of their counsellor/psychotherapist and focus more on skills, although an atmosphere of trust has likely developed and is implied. For example, Charles shares that "mindfulness exercises/checking in with [himself]" at the outset of sessions makes a difference, Jake finds the "scientific approach" to understand his "stress points" "reassuring" and Marie experiences listening on the part of her therapist as a "relief" (242, 243, 244). Both Jake and Marie share that it is helpful to reach out to someone beyond family to express their concerns (245). Like focus group two, co-researchers in focus group three speak to valuing the skills of their counsellor/psychotherapist, the ability to engage in reciprocal dialogue. Implicit is the spirit of collaboration that allows for this dialogue, with Charlene refering to her therapist as "authentic" and Jake appreciating his therapist's "better approach to dialogue … back and forth … a more nuanced thing."

7.b Counselling and Psychotherapy Experiences –Unhelpful Experiences. Regarding focus groups one and three and the common super-ordinate theme and subset: Counselling and psychotherapy experiences –unhelpful experiences, the sharing of co-researchers' stories brought on powerful emotions. There is a common thread across groups which confirms the portrayal of persons with disabilities by disability theorists: they are talked at and decided for (Bassler, 2009, 2014; Hultberg, 2012; Reicken et al., 2005; Stone & Priestley, 1996). Persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities face the further disadvantage of not being believed because their struggles are less apparent. The nuance of their experience goes unrecognized (Bassler, 2009, 2014; Davis, 2005; Hultberg, 2012; Reicken et al., 2005; Shakespeare, 1996; Sharma et al., 2020; Stone, 1995; Valeras, 2009, 2010). Co-researchers

in focus group one share their unhelpful experiences with one another, which generates intense feelings and a great deal of discussion. Alice first recounts an unhelpful experience where the therapist fails to paraphrase (likely not listening) which results in her feeling "misunderstood" and "putting up a wall" (246). This is followed by most in the group taking exception to being pushed to do things that are not in alignment with their needs and respectful of them as self-informed persons (247). Co-researchers in focus group three similarly speak to their unhelpful experiences passionately and as a matter of catharsis. There is a theme of feeling discounted, whether it be a psychiatrist as "drug pusher" (instead of getting to the root of it), a therapist who keeps talking (failing to realize that you're having a "shitty" day), a counsellor who asks, "are you sure that's really how you feel?" (instead of believing you), or a therapist saying, "you should be happy that you're alive" (instead of understanding that everything's not "sunshine and rainbows" on a regular day) (248, 249, 250, 251).

8. Feedback and Suggestions re: PAR Methodology. The eighth super-ordinate theme, "Feedback and suggestions re: PAR methodology," has two subsets: 8. a General comments and dissemination of results; and 8.b Fostering a sense of community. Focus groups one, two and three have both subsets in common.

8.a Feedback and Suggestions re: PAR Methodology - General Comments and Dissemination of Results. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Feedback and suggestions re: PAR methodology - general comments and dissemination of results, there is a consensus among co-researchers across the three focus groups that by using PAR we are capturing what we are after in this study- developing A Patient-Centred Framework for Counselling and Psychotherapy with Persons with CF. The benefits of PAR for the framework include: the conduciveness of the focus group format to an atmosphere of

sharing; and the basic assumption that the framework be based on the wants and needs and experience of those living with CF (RD) rather than on "science" or doctors' opinions. Regarding sharing the patient-centred framework with other CF patients at the Ottawa clinic and requesting feedback from them before finalizing it, all co-researchers agreed to this idea, albeit focus group three suggested that we also enlist the feedback and support of the CF clinic nurse coordinator because "if the doctors aren't listening to us …. the nurse practitioners are … we need them" (252). Reasons for sharing the framework and including the feedback from other CF patients include: the benefit to them, including feeling "validated," "less judged" and "connected;" and the benefit to the framework, with their feedback making it more robust and adding "a stamp of approval." With respect to the dissemination of the framework, co-researchers consistently made the distinction between sharing the findings with counsellors/psychotherapists and patients, suggesting disparate modes of communication dependent upon the target group.

Co-researchers in focus group one agreed that the PAR methodology employed in this study has been advantageous to developing the patient – centred framework for the following reasons: the focus group format provided "inspiration to talk" and was "more personable" then, for example, "just having them give you a questionnaire;" they appreciated being asked about what they "really need and want;" and where there had been a gap in sensitivity to the connection between mental health and chronic illness this project highlights this point. One co-researcher commented on the need to "roll with the questions" for the good of the study (253, 254, 255, 256). Regarding sharing the patient-centred framework with other CF patients at the Ottawa clinic and requesting feedback from them before finalizing it, there was agreement to share it so that others could feel "less alone," "inspired," "validated," "less judged," "connected" and to get "a different perspective" and "stamp of approval" "for the benefit of everybody" (257, 258, 259). With respect

to the dissemination of the framework, co-researchers made suggestions in alignment with the two principal target groups, CF (RD) counsellors/psychotherapists and CF patients. Professional conferences and journal articles were preferred for the former while providing pamphlets/resource packages at transition visits from CHEO or creating social networks across CF teams, were considered beneficial to patients (260, 261, 262, 263). Co- researchers in focus group two also agreed that the PAR methodology employed in this study has been advantageous to developing the patient – centred framework for the following reasons: the focus groups allow "people with like minds to share ideas;" and "people who have the disease" are better to portray their experience then doctors "who don't live with it every day" (264, 265). Regarding sharing the patient-centred framework with other CF patients at the Ottawa clinic and requesting feedback from them before finalizing it, there was agreement to share it because there is learning in sharing, maybe other persons with CF (RD) have good suggestions and there would be "a larger pool of data ….it would continue to improve things for the benefit of everyone" (266). With respect to the dissemination of the framework, co-researchers again made the distinction between "getting the word out" to counsellors/psychotherapists/medical professionals versus patients. Journal articles to create continuity of care in the realm of counselling across Canada, technical/published papers and "CF forums and conferences" for professionals were preferred whereas pamphlets (after some discussion), short videos, creating a national registry for CF information sessions and group meetings as well as making the framework available on the CF Canada website were favoured for patients (267, 268, 269, 270, 271, 272). Co- researchers in focus group three agreed with the rest that the PAR methodology employed in this study has been beneficial to developing the patient – centred framework for the following reasons: the framework need be based upon the feedback of people living with the illness who know about their bodies and what they need rather than derived

from doctors or "just on science." This is particularly important because CF is a "spectrum" and people can be "messy" sometimes. One of the co-researchers, Charlene, expressed that PAR "actually [made her] believe you that you care about our answers and care about our opinion." Both co-facilitators shared their experience, which had been positive, with one pleasantly surprised at the extent of her involvement, and the other stating that she could have benefitted from a more defined role (273, 274, 275, 276, 277, 278, 279, 280, 281). Regarding sharing the patient-centred framework with other CF patients at the Ottawa clinic and requesting feedback from them before finalizing it, this did not generate discussion, however, Karen recommended that crucially the CF clinic nurse coordinator weigh in and be involved so that other patients can benefit from their "hiccups" or past experience (282, 283). With respect to the dissemination of the framework, co-researchers again made the distinction between counsellors/psychotherapists and patients and suggested separate modes of distribution. For example, Charlene and Karen focused on the delivery of the framework to patients, with the former thinking it beneficial to "present [it] to the Ottawa CF community" as a means of communication, and the latter concerned that communication have "a visual and formatting component" to stand out from other emails. Jay was concerned about the credibility of the framework and that it be substantive for CF psychotherapists. He proposed that it be published in a journal along with the "clinical background" and "research methodology" of the study (284, 285, 286).

8.b Feedback and Suggestions re: PAR Methodology - Fostering a Sense of Community. Regarding focus groups one, two and three and the common super-ordinate theme and subset: Feedback and suggestions re: PAR methodology - fostering a sense of community, all co-researchers across focus groups experienced a sense of community as a result of sharing their experiences with like others in the context of a PAR focus group. This helped them to feel

"connected," "validated," "understood, valued and heard" and to some allowed for levity and a collective unburdening. Many wanted to continue communicating with one another via social network forums, perhaps as an outgrowth of the framework, or informally beyond the scope of the study. Their enthusiasm likely stemmed from social and existential isolation, having been denied the opportunity to share their perspectives more intimately with others with CF (RD), they now had the opportunity to do so (van Bruggen et al., 2017).

Co-researchers in focus group one ultimately had a positive experience that fostered a sense of community. For many this was the first time they had interacted with others with CF (RD) in a meaningful way. Being together in a focus group allowed co-researchers to "connect," find "common ground," "perspective," and normalize their experience (287, 288, 289). Through the process they supported one another in the telling of their stories which helped them to feel "understood, valued and heard" (290, 291, 292). The sense of community fostered in focus group one prompted co-researchers to consider participating in pre-existing online forums (CF Ties) or formalizing social networks as part of the patient centred framework, to connect as a CF community (293, 294, 295). Co- researchers in focus group two commented upon the benefits of PAR in fostering a sense of community. Being together in focus group gave them the opportunity to share their experiences, learn from one another and feel connected, to the point of potentially reaching out beyond the parameters of the study (296, 297). Co- researchers in focus group three spoke about the benefits of PAR in fostering a sense of community and as a counterpoint to the isolation they typically experience from others with CF. As they "resonated" with one another regarding coughing and COVID and other subject matter, there was a lot of levity and shared laughter possibly helping them to cope (298, 299, 300, 301, 302, 303). Like focus groups one and two being with like others helped to validate and normalize their collective experience which felt

valuable (304). Two co-researchers, Jay, and Kallie were so moved by the group that they saw it as an opportunity to unburden (305, 306).

8.3 Section One: Semi-Structured Interviews Vertical Analysis

This section of the thesis focuses on what co-researchers are expounding upon (adding, emphasizing) over and above their contributions in focus group. The six semi-structured interviews are presented in narrative format and in chronological order. Presenting findings in a narrative format puts the people who are being interviewed at the heart of the story, rather than super-ordinate and emergent themes. It creates more of an intimacy to better understand their experiences (Seidman, 2019). Seidman's (2019) words are apt here:

> I have found crafting profiles, however, to be a way to find and display coherence in the constitutive events of a participant's experience, to share the coherence the participant has expressed, and to link the experience to the social and organizational context within which the individual operates (p. 129).

Presenting the findings of the semi-structured interviews in a narrative format adds a richness to the stories of Charlene, Kyle, Alice, Jake, Karen, and Veronica as well as to their recommendations for CF (RD) counsellors/psychotherapists and other CF (RD) interdisciplinary team members. It is important to note that some quotations have been taken outside the context of the focus group or semi-structured interview, for example, brief comments or feedback, and because they are relevant have been included here.

8.3.1 Charlene. November 5, 2020

Charlene volunteered to be a co-facilitator for focus group three (CF 18-30). She shared in the introductory icebreaker exercise that she works in mental health and that she was "supposed to get married this year, but that got delayed [due to COVID]." Otherwise, a "little fun fact is that

[she] plays violin." She was 30 years of age at the time of the study, had been diagnosed with CF at six months old and has a graduate degree. Charlene identifies as a person with a non-visible illness/disability, stating the following in her response elaboration:

> Considering the amount of time needed for medical treatments on a daily basis, as well as the frequent absences due to exacerbations or hospitalizations, I consider it a disability as I have required medical accommodations as a result. I also think that our constant coughing and need for treatments or adjustments to our routine does have an impact on our living in society and is an additional obstacle to living and functioning normally.

She has had previous counselling/psychotherapy experience, commenting:

> I have used counselling services twice in the past. Both instances were short-term services. First time was for panic attacks unrelated to my health. The second time was related to coping with challenges and systemic issues in getting support throughout illness, including disability insurance, financial support, and access to medication. What I found helpful was to identify and understand better the various resources and supports that could be used alternatively if insurance and medication access were restricted, but also exploring my fears behind it, in order to be better prepared.

At the outset of her semi-structured interview Charlene shares another personal characteristic stating, "punctuality is not my forte … this is my one vice … you know, as not a robot and a human being who's imperfect my one vice that I allow myself is to not be punctual (laughs)." At the end of the interview, Charlene expressed that she appreciated the opportunity to meet one to one because she "was able to … say a lot of the stuff that [she] didn't want to burden time on with the focus group" (1).

Participating in focus group helped Charlene to see that CF "really did impact [her] day-to-day life," particularly her family dynamics as she moved through adolescence and tried to develop independence and a sense of self. The need for independence peeked in her transition to adulthood but was complicated by the severity of her illness and her mother's "overprotectiveness" or reluctance to fully let go. Learning to become independent in one's care and parents' ability to trust that one can do so is a developmental issue that many CF families face. There are real concerns here as CF necessitates complex treatments and one's health can fluctuate and decline without warning complicating the process of individuation for both parents and child (Cystic Fibrosis Foundation, n.d.):

> It was really interesting to hear what others had to say that I didn't even think about. But it's true. It does impact our day-to-day life. You know, especially when it comes to like, for example, relationships or family dynamics … I used to fight a lot with my mom, and you know her being very overprotective and me trying to be more independent … The concept of independence was a huge issue for me that I wanted to be independent, but I felt like I didn't have the skills or the opportunities to learn how to be independent because of my disease and because of my mother being overprotective … Steady job … school … career or a relationship …those were things that I was really scared about. Yeah, both in the sense that I wasn't sure if I would be able to have it, but also in the sense of I wasn't sure if I even had the skill sets to do that because I was never prepared for that because everything like I was always being taken care of by others, right? (2, 3, 4, 5, 6, 7).

In terms of her "struggle for independence" Charlene found herself at one point "probably depressed" as she was "so unhappy with a lot of things in [her] life" (8). The way she eventually "turned things around" was to "force [herself]" to change aspects of her life over which she had

control unlike her illness. The result had been "empowering" (9). For example, Charlene had not had many friends in high school in large part because of the fluctuating nature of her illness and the way she "pushed through that … was to … do things that would give [her] opportunities to … be social," for example, volunteering (10). Even while CF is life limiting exercise can help those with the illness to expectorate and improve their lung function, therefore they are encouraged to do so (Cystic Fibrosis Foundation, n.d.). Charlene started exercising vigorously which changed the trajectory of her illness so much so that she experienced a "five-year break in hospitalizations" (11, 12). Charlene again brought in the aspect of CF that she "hates" the most and that is "fighting the bureaucracy of it all," the fact that even though feeling sick and vulnerable "you're the one who has to tie it all together and fix those problems," for example, coordinating one's care or securing access to medications. This, she points out, is particularly relevant when trying to procure the care of specialists beyond CF clinic. Here too Charlene learned to distinguish those aspets of life that were within her control, for example, "reaching out to [her] MPs." Since Charlene had been an overprotected child, it is understandable that overcoming challenges and learning to successfully navigate healthcare systems, although "sometimes pretty overwhelming" nonetheless provided her with a sense of purpose and made her "proud of how far [she'd] come" (13, 14, 15).

The need to feel in control of her situation and the possibility of feeling sick and vulnerable and not getting the support one needs, are continuous concerns for Charlene, and she repeatedly refers to these throughout her interview. She reiterates that having a non-visible illness/disability means that one can control whether to conceal or disclose CF and in what context (16), which is advantageous. However, what she elaborates upon here, is that "there are fallbacks as well," for example, if she requires a handicapped parking space, people "can key [your] car" because they "don't understand … I can walk fine but that doesn't mean that I can walk fine, you know?" (17).

Getting into a conflict situation when feeling "sick and vulnerable" is understandably untenable (18). Charlene then refers to situations where she has not received the support she needed "even when sick … because people don't believe you" (19). For example, in a work situation an employer had been "super super rude" when he found out that she would require imminent hospitalization and fired her (20). This experience and others inform her employment practices in that she has decided to choose any future employer based on their flexibility, "allowing for priorities related to health" (21, 22, 23, 24). Charlene also had a negative experience when reaching out to a previous counsellor at the CF clinic. Whilst setting her needs and this resource aside so that others might benefit, when she finally reached out for help, there had been "no connection or follow up … which was a real downer" (25, 26). She likewise had been told by a CF nurse, "you're not dying so you're okay … which made [her] feel worse" (27). Based on these experiences, Charlene is emphatic that caregivers do not assume that "because [you're] physically doing okay … you're mentally doing okay" (28). What she wants to avoid is "people feeling like they're not gonna do anything because [you're] not sick enough" (29, 30). Even when reflecting upon CF's positive aspects and meaning and purpose in life, Charlene returns to the themes of control and having the support one needs when most vulnerable. For example, she states, "it is important with that sense of control … making the most of the time we have … and to choose people … that would be there for me and present for me in times of need" (31). Perhaps due to her concerns, the following statement by Charlene is particularly poignant. While she first asserts that CF has finally allowed her to "let go of things easily" and to "appreciate more every moment," here she emphasizes that CF has made her appreciate that "life is not all positive and perfect" and to embrace challenges as "beautiful," the culmination of her learning (32, 33):

> And the last thing that I would say that's positive about CF as well is that it's also kind of given me … It's allowed me to realize that life is not all positive and perfect and happy, and that's OK you know, like I think, part of like life includes challenges, and it includes hardships, and it includes fears and all that is a part of life. And that is a beautiful part of life too, you know. So those obstacles that you overcome are beautiful when you can overcome that, you know together and when you find ways to overcome those challenges, those are really beautiful and impactful and powerful, and those are things that I've observed in my life (34).

Finally, based in her experience, Charlene has four principal recommendations for CF counsellors/psychotherapists: 1) have an empathetic solution-focused approach which is helpful "to plan and better be prepared;" 2) if outside the hospital setting, "get informed about what CF is … just because someone appears to be healthy it doesn't mean that they aren't suffering from a mental health perspective;" 3) have "some sort of existential discussion on what CF means … like the meaning of CF or the meaning of life … because CF touches so much on death and mortality, and that's such a big factor." She continues that "persons with CF might benefit from an existential discussion if they are depressed, if it's someone with whom the therapist has developed a relationship or if engaged in long term therapy;" and 4) "meet each patient where they are at because they all have … different experiences and different needs and are at different stages. Focus on whatever aspect of their life they require" (35, 36, 37, 38, 39). These recommendations have been incorporated into The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

8.3.2 Kyle. November 10, 2020

Kyle did not volunteer to be a co-facilitator in focus group two (CF 39 +) choosing instead to "just be part of the process." He shared in the introductory icebreaker exercise that he had grown up in Eastern Canada, "worked for a computer company for 18 to 20 years and just turned 47." He had been on the double lung transplant list but started Trikafta in March 2020, based on compassionate grounds, just six months prior to this study. Being on Trikafta has been "a huge game changer" for Kyle and he expounds upon this topic in his semi-structured interview. Kyle had a late diagnosis of CF at nine years of age, is divorced, lives alone and he is a student in an undergraduate medical program. This will be his second undergraduate degree. Kyle identifies as a person with a non-visible illness/disability, stating the following in his response elaboration, "Yes, I have cystic fibrosis and people are not able to notice the difficulty walking, difficulty breathing and most times the amount of coughing." He has had previous counselling/psychotherapy experience, commenting, "Yes, I have seen a relationship therapist about times and a therapist at the cystic fibrosis clinic for several months." At the outset of the semi-structured interview, Kyle added that he really enjoys the course he is in and learning about phages. "Phage therapy is in its infancy in Canada and uses a virus to treat bacterial infections. It may help those with CF on a case-by-case basis with drug resistant infections," and therefore prevent significant lung damage. Kyle later mentions that learning about phages "gives him a sense of purpose and meaning in life." His excitement is palpable in the following quote (1):

> I'm fantastic. I'm learning all about the heart and how it works and the blood supply and all that stuff there. And electric currents or not. It's interesting. It's fun, I really enjoy it. And I finished all my lab work about my phage that came back and took the transmission electron microscope photos of it. Looks pretty cool (2).

At the end of the semi-structured interview Kyle states that it had been "thorough." He emphasizes that participating in focus group, however, helped him to meet others who had gone through lung transplantation, and he thanked this researcher for "bringing awareness to this cause otherwise I wouldn't have known other people going through transplant" (3). The real significance for Kyle of meeting others who had gone through transplant is twofold. First, he had narrowly missed transplantation when he was approved for Trikafta, which improved his lung function enough to "bump [him] off the [transplant] list." Second, he had been told about the "pros and cons" of transplant, for example, "the medications are going to cause problems physically, mentally," however, "until you speak with someone who's been there and shares their story, you don't have the emotional impact." Hearing others' stories helped Kyle to reflect upon his own journey and "invoke the okay, I gotta fight for that not to happen to me" (4, 5).

The benefits of sharing the "stories" and "narratives" of those with CF is an important idea for Kyle which he repeats throughout his interview. For example, he recommends that members of the interdisciplinary team "tell other people's stories" to CF patients at clinic appointments, to help them to integrate the mental health aspect of the illness. The telling of stories would impart a more "all-encompassing understanding of CF … regarding progression … medications … personal relationships and emotions and would help people to prepare" (6, 7). Similarly, Kyle recommends that CF counsellors and psychotherapists share stories with CF patients to inform them of common mental health concerns and normalize seeing a therapist. The sharing of other people's stories, when it occurs, has helped Kyle to move beyond "I'm fine, happy all the time" to "I'm going to experience the same stuff" (8, 9, 10). The normalizing of seeing a therapist is particularly important to Kyle because when he first told his parents that he was seeing one he was met with "blaming" and stigma, "they were like what do you need to see a therapist for?" When he impressed upon

them that CF was impacting sexual intimacy with his partner, "a difficult subject to broach," they finally conceded (11, 12).

Talking about his experience "more openly and freely" with a counsellor/psychotherapist has helped Kyle to let go of "not feeling good enough for certain aspects in life like relationships" and instead have "a sense of self-worth" (13, 14). Feeling "not good enough" is an underlying psychological and existential concern for Kyle, touching upon death, meaninglessness, guilt, social isolation, and identity, which he talks about in the focus group and mentions briefly here (van Bruggen et al., 2017). It calls to mind the quote in Marseille and Messias (2020) summarizing existentialism, "Man is an existential being whose life is more than logic and who must discover the meaning in existence" (p. 394). Being in psychotherapy has been part remedy, helping Kyle to feel more comfortable talking about CF and his well-being, "whereas before [he] was never comfortable talking to anybody … now sometimes [he] feels bad about talking about it too much" (15). One of the aspects of CF that Kyle touches upon is the difference in his day-to-day experience "post and pre Trikafta," stated most eloquently here:

> Break it down to like post and pre Trikafta … so post Trikafta now is basically just having joy in little things like being able to put on socks. Being able to sweep the floor without getting out of breath. Being able to walk. I see a set of stairs and it's like yes gonna do these guys. So, it's excitement about that. Where before it was like oh stairs? Where is the elevator? (16, 17).

Based in his experience, Kyle has the following recommendations for CF counsellors/psychotherapists: 1) have an introductory meditation exercise, perhaps "with the sound of trickling water," which is "calming" and allows for "clearer thinking;" 2) write down and reference notes, which helps to "keep track of things;" 3) "recommend materials, such as books

and articles" relevant to learning; and 4) include a "future aspect," reiterate "what I can do now or want to talk about next time (18)." These recommendations have been incorporated into The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

Finally, regarding feedback and suggestions re: PAR methodology, general comments and dissemination of results, Kyle submits that having Charles, a person with CF, co-facilitate the focus group and share his experience, "made things flow" and "feel a bit more comfortable … like you're writing a paragraph … last sentence leads into the next sentence" (19, 20, 21). His reference to "paragraphs" and "sentences [leading] into the next sentence" is symbolic given Kyle's preference for hearing the "stories" of others with CF, thereby feeling less alone. Kyle posits an original suggestion, beyond the sharing of stories, that might help sensitize those with CF to the mental health aspects of the illness: "a five-minute questionnaire to distribute at clinic appointments spread out over time, with an explanation after and follow up." Poignantly, one of his proposed questions might be, "do you feel like you're not good enough?" (22, 23).

8.3.3 Alice. November 10, 2020

Alice volunteered to be a co-facilitator for focus group one (CFRD). She shared in the introductory icebreaker exercise that she "is a creative person" and plays the guitar, loves cooking, baking, sewing, crafting, woodworking and "all things do it yourself." At the time of the study, she was 25 years of age, partnered, was living with both her partner and a roommate and her employment status was unemployed. Alice had been diagnosed with CF at two months old and has both an undergraduate degree and college diploma. She identifies as a person with a non-visible illness/disability, stating the following in her response elaboration, "CF and CFRD are both invisible illnesses – no visual indicator of either." She has had previous counselling/psychotherapy

experience, commenting, “I have seen the CF social worker … for the last four years, but more consistently in the last one and a half years. Additionally, I was seeing a private therapist … for five months in 2019.” Alice shared at the outset of the semi-structured interview that she was just getting past her most recent infection and had completed a two-week course of antibiotics. She is feeling “tired …. but pretty good … wasn’t doing too hot, but better.” For Alice, feeling good is relative at this stage in her illness. She elaborates on this point in her semi-structured interview (1). At the end of the interview, Alice expressed gratitude for the opportunity to meet one to one stating, “it was so much fun.” She also asserted, “I touched on all my grievances and everything I wanted to talk about.”

Participating in focus group had been “life changing” for Alice because she had previously felt that she had been “existing in a vacuum,” isolated from others with her illness. She subsequently shares her experience serendipitously meeting a co-researcher in clinic with whom she had “connected” after the focus group on Facebook. For Alice, the experience of relating to someone, having a sense of community, is a natural outgrowth of the study (2, 3):

> Yeah, I think it was helpful to have a group setting. Like a focus group because you know sometimes I feel like I exist in like a vacuum and nobody understands or kind of feels what I do. So, having that connection with other people and being able to hear their different stories and connect with them over it was like, yeah, completely life changing I think … and I had to go upstairs to clinic to give in my mucus sample and while I was up there, I wasn't supposed to be seeing anything. I was literally dropping it off … and so, we've been like chatting on Facebook and I heard her like speaking in her room with the door open. So, I messaged her right away and I was like oh my God, are you here? I'm here. I'm not supposed to be here, I just had a shit visit. I'm happy to hear yours is going well. Come say

> hi before you go and so we met in person for the first time, and she stood kind of down the hall, and we talked out my room door and that was really fun. Yeah, and it wouldn't … happen I would have no idea who she was, anything, if it weren't for the study. So, that was fun.

The opportunity to connect with another with CF (RD) felt particularly meaningful to Alice as she had been adjusting to her new "day to day" after a decline in her health these last three years following her first hospital admission (4). Whereas previously she had "not shown any physical symptoms of having CF," and "pushed past it" engaging in sports and other activities now life "is a little slower … a little bit more restrictive … and a pretty big mental battle" trying to integrate this new version of CF (RD) into her identity (5, 6, 7, 8). Alice reflects upon how COVID has exacerbated her experience of feeling other than, since "most decisions around [her] household are based around keeping [her] safe … which is sometimes a difficult burden" (9, 10). Having a fluctuating chronic illness especially during COVID has meant that Alice "teeters the line of normal and not normal … between healthy and not sick person," whilst balancing her own expectations of herself with that of others including family. For example, she states, "it's been a back-and-forth battle between being safe and being around family," who may prioritize missing her over precautionary practices. Prioritizing her own need to be safe can sometimes bring on "feelings of guilt and resentment" (11, 12, 13, 14, 15).

The fluctuating nature of CF (RD), and the fact that "it changes over time" leaves "way less wiggle room to be a regular human being" and this is something that Alice finds "really difficult especially when at the bottom of it" (16, 17). The downturn in her health has taken a "real emotional toll" in that she feels "guilty … did I somehow along the way stop caring for myself? … Can I be back there? What the heck is it going to take for me to get there?" (18, 19, 20). This

sense of control over one's health reflects the responsibility that is placed upon those with CF (RD) who are considered experts in the daily management of their illness, which they then internalize (Cystic Fibrosis Foundation, n.d.). Having experienced the recent decline in her health and feeling that she is falling short of expectations Alice seems confronted with the existential themes of life and death, responsibility, accountability, uncertainty, guilt, and the I-am of identity (Marseille & Messias, 2020; van Bruggen et al., 2017; Yalom, 1980).

Alice's issues with the downturn in her health continue to be a theme throughout her interview and are compounded by the fact that, by her own admission, she is "other oriented … [she] sees [her] problems less in terms of the problems that [she] faces and more in terms of how other people have problems with [her]" (21). So, for example, she speaks to her partner's and an employer's responses to her health situation, focusing more on their reactions than her own thoughts, feelings and needs. In the first instance, she refers to her partner who "is very valid in being scared and valid in not necessarily questioning me but like questioning the kind of future we're going to have." She references her partner's need for "big conversations" around life expectancy and having biological children that put "future stress" on their relationship, however, minimizes the fact that during a confrontation she is feeling ill which "takes a little bit of a toll" (22, 23). Likewise, she expounds upon a work situation where she "had to deal with the judgements and assumptions of others" and attributes their insensitivity to her illness/disability being non-visible (24). Whilst she does mention this situation being "jarring" and "embarrassing" she is more engaged in the telling of the story and the judgement of others than in her felt experience (25). When she is finally let go Alice's initial reaction had been to question the viability of working full time with CF. Instead, in a turn of events, she filed a "Canadian Human Rights complaint … and received a settlement for wrongful termination based on [her] disability." This was a turning point

for Alice culminating in her feeling empowered and turning her attention to her own needs, deciding to be more discerning regarding future employers (26, 27).

Perhaps as a point of contrast to Alice's current state of health and her degree of acceptance, which is a "process," she highlights "the positive thing about CF … what gave her a sense of meaning and purpose," particularly when young. She notes that CF had given her the opportunity to tell her story at fund raising events and "make a difference … that it's made [her] more resilient" (28, 29, 30). Here, Alice's attitude and actions recall Frankl's core principle of self-transcendence, finding ultimate meaning by rising above one's suffering and helping others (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014):

> So, it's always been this like positive thing and that it gave me a sense of purpose and meaning to tell my story and to be super impactful to lots of people who were able to fund raise and make a difference. I yeah, I think, yeah, as much as I resented it, I do derive a lot of meaning and purpose from being able to tell my tough story. But not in a negative way to like completely demonstrate all the positive things we can still do and you know the difference we can make and yeah. So, I think of positives yah I think that's it just being impactful being able to tell my story has been such a privilege and I've literally loved it … it's made me more resilient … it's definitely tough, but I wouldn't necessarily take it back.

Alice speaks to her helpful counselling/psychotherapy experiences, elaborating upon some mentioned in focus group and arriving at a conclusion. Expounded upon helpful counselling/psychotherapy experiences include: 1) the benefits of being able to sit with her "negative emotions … and vocalizing something for the first time … which feels like someone is pulling a demon out of me or lifting a weight off my shoulders;" 2) receiving feedback regarding positive progress which is revelatory and "fun … making for a good encounter;" and 3)

experiencing “light bulb moments … that ooze out” and writing these insights down to reference later. This has become a personal resource and has had the effect of “changing [her] internal dialogue” (31, 32, 33, 34, 35). The conclusion Alice arrives at regarding the role of counselling/psychotherapy in her life: “therapy allows for the processing … [of CF related] stuff … which really helps in the day to day” (36).

Based in her experience, Alice has the following recommendations for CF (RD) counsellors/psychotherapists: 1) “it is important to recognize that all of us need help. All of us should be seeing someone … I had this dark thing inside of me that didn’t really show but it sat with me;” 2) “have the ability to get me to ask myself important questions;” 3) “be able to regurgitate the information I just said in the most complicated, confusing kind of way and then have it actually make sense;” 4) “be open about a little bit of [your] personal history … so that it feels like [our] connection is a bit more human and not so much like [I’m] dumping my problems on you;” 5) “be “well educated … understand not only about chronic illness but specifically CF because we’re grappling with a big underlying issue that is likely impacting all of our experiences;” 6)“tell me stories sometimes about other patients [with chronic illness and/or CF] … because that opens this space for those conversations;” 7) begin the session with a “grounding meditation … sitting alone with your thoughts for two minutes … really helps;” and 8) “provide some tangible resources … or exercises … that are digestible to take home so that lessons don’t only happen in the office … and I can literally apply them to everything” (37, 38, 39, 40, 41, 42, 43, 44, 45). Alice’s last recommendation is directed at CF (RD) counsellors/psychotherapists and CF (RD) doctors, nurses, and all allied health. The main idea is that there should be a synergy between those that provide mental health services and the entire CF (RD) interdisciplinary team, so that “everyone’s on the same page” (46, 47, 48). These recommendations have been incorporated into

The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

Finally, regarding feedback and suggestions re: PAR methodology, general comments and dissemination of results, Alice again mentioned that the focus groups helped people to connect and have a sense of community. She had this observation about meeting collectively on MS Teams, "I liked it, it took the potential judgement out of it … I think people were able to speak … more vocally to their screens than to our faces if we were in the same room" (49, 50). Alice also thought that it might be beneficial to consult with the support systems of people with CF (RD), for example, families, at a future date to "see their perspective on how we struggle with it … and understand the background decisions that help shape our mindsets of chronic illness." Understanding the backgrounds of people with CF (RD) might help to appreciate "how people can support people with chronic illness better" (51, 52, 53, 54, 55). Concerning sharing the patient-centred framework with other CF patients at the Ottawa clinic and requesting feedback from them before finalizing it, Alice initially had an "egoic" response, "they didn't put the work in." However, she then stated, "it's important for everyone to have approval. Also, if we're struggling with it … then other people are feeling the same way … ultimately, it's to help our whole community … it opens up a dialogue which is an important part" (56, 57, 58, 59). With respect to the dissemination of the framework Alice had the following original ideas: 1) have "an onboarding process … for patients when you come to the General from CHEO … emphasizing the resources for counselling and the importance of it … it comes back to doctors … integrating social support into our health care picture;" 2) have a "ramp up process … a way to give a little bit of a taste [of the benefits of counselling] but not overwhelm you … so you just keep coming back for more." This would be helpful "when people express interest for the first time and if emphasized when they switch to adult clinic;" 3) implement

"onboarding for therapists … especially because every CFer has a different experience … have them learn those big themes;" and 4) have a "cheat sheet for CFers … as part of the onboarding … to give examples of common things that we all feel to feel validated … Oh, I'm struggling with that. I didn't know other people were too … a thought cloud of hard concepts" (60, 61, 62, 63, 64). Alice's recommendations regarding the dissemination of the framework have also been incorporated into The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H). It is worth noting that some of her recommendations are being implemented already as the finalized framework acts as a "cheat sheet" to "onboard" interdisciplinary team members to the mental health and counselling needs of our CF patients.

8.3.4 Jake. November 11, 2020

Jake did not volunteer to be a co-facilitator in focus group two (CF 39 +) choosing instead to "sit back and see how [he] can contribute." He shared in the focus group introductory icebreaker exercise that he was 39, was diagnosed with CF "at either a week old or a few weeks old." Further, he works for the government and 10 years ago "got a double lung transplant so, [he's] 10 years in." Jake is married, lives with his spouse and has a college diploma. At the outset of his semi-structured interview Jake shared that he could "split [his] life" with CF (RD) into pre- and post-transplant, ages zero-30 and 30-39, with his life before 30 "feeling more under control." Having had a double lung transplant has been "life changing" for two main reasons. First, he no longer needs to do physiotherapy exercises to clear his damaged lungs twice daily, which had become his routine (1, 2). Regarding his treatments and other aspects of his pre-lung transplant life, Jake sometimes "felt sorry for [himself] … why was this lot handed to me?" (3). He elaborates that he "couldn't imagine going back to that … but push comes to shove [he] would because sometimes

the will to live … the human resolve is pretty amazing" (4). Here, Jake's attitude exemplifies Frankl's will to live, ultimately choosing not to feel "sorry for [himself]" but instead to "persevere" (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014); The second reason that having a lung transplant is "life changing" is less known, unseen, but no less impactful. By way of explanation, Jake shares the following:

> When you get a lung transplant, you're trading one illness for another … your lungs are better, but because of all these anti rejections you now have diabetes. You now have osteoporosis. You might have liver problems. You may have kidney problems (5).

Jake shares the secondary effects of lung transplantation during the interview to illustrate the difficulties he is up against having a non-visible illness/disability and having been chastised for occupying a handicapped parking spot, "because I may not look like I belong" (6). However, more poignant is that Jake in fact has all these secondary health complications which has been "devastating" at times. In his response elaboration regarding identifying as a person with a non-visible illness/disability, he states, "I also have … diabetes, osteoporosis, fatigue." He asks to "keep [the interview] quick" as he had been having "gastrointestinal issues" and ingesting PEG Light, a laxative meant to clear out the bowels before a bowel exam procedure or x-ray. Shortly after this interview, Jake discovered that he had to have a liver transplant, which he has survived. Regarding participating in focus group Jake would "be part of [one] in the future" but notes that he would have to "bite [his] tongue if there's people in there you might not agree with … like there was one person who is not an expert in the field who was giving unsolicited advice" (7, 8, 9). Jake had been the only co-researcher in focus group two who marked "no" to having had previous counselling/psychotherapy experience, commenting, "when [he] has problems [he] mostly talks it out with [his] wife." It is worth noting that Jake aspired to be "a journalist or a writer for articles

or magazines" but "it became apparent to [him] that [he] needed a job with the government" to have access to healthcare coverage because of his illnesses (10). This theme of having to subvert his preferred identity due to CF (RD) and wanting to be known as a person first apart from his illnesses is prevalent throughout his interview. In honour of Jake's aspiration to be a writer, and his acknowledgement that he is "good with words," this researcher will therefore impart much of his story in his own words by way of extensive quotations.

Jake begins by relaying an experience in which a grade one teacher disclosed that he had CF to his class and therefore betrayed his trust:

> My teacher asked me do I want to tell the rest of the class I have cystic fibrosis, my peers and everything. And I was very firm, and I said no, I do not want them to know I want to be treated like everyone else. Regardless, she went ahead and told them anyways (11).

This had been particularly egregious because Jake would have chosen concealment over disclosure as he wanted to be treated "like everyone else" (12). CF (RD) may be part of his life; however, his identity is not limited to CF (RD). He uses a beautiful and meaningful metaphor to convey his felt experience:

> It was during elementary and high school I had the hardest time, well more so high school. And then another thing was dating girls. I didn't want them to know I had cystic fibrosis … I didn't want to be judged based on my illness even though I'm sure everyone already knew. I didn't I didn't want to. Didn't want that to identify me as I'm Jake with cystic fibrosis. I wanna be, I'm Jake … the guy who draws really well and likes comic books. And you know, friendly guy to hang out with … I'd participate in gym as much as I could, but I'd get a pass … Teachers weren't so hard on me … However, I'm pretty sure there's some that didn't know, so they pushed me just like everyone else and I actually like that cause I

felt OK, well you know I'm a normal person. That's really what you want to be. You want to be a real boy, right? Like Pinocchio, you want to be a real boy (13, 14, 15).

At an early age, Jake felt "ashamed of having cystic fibrosis," in part due to his mother's parenting and negative attitude toward his illness. This, in addition to the instability of his father's employment, led Jake to feel "conflicted" and drove him to "become a productive member of society." All told, this is a tremendous existential responsibility for a child:

> But I was kind of very I was very ashamed of having cystic fibrosis. And, uh, that's an important thing I should probably touch on. I was ashamed of it and I felt that I was a burden on society. Now that I'm older, I realize that that was not the right way to feel. Because it's not my fault. As you know genetics. I didn't. There's nothing I did as a kid that predetermined me to have cystic fibrosis … and the more I reflect on it, the more I think … it has everything to do with my mother … she would very much like to play the martyr to anyone who would listen … she was always talking about how rough it was you know, bringing me up and how hard she struggled and whatever. Meanwhile my dad, who you know who held the job and did my physio twice a day and still found time to play with me. He never ever complained about it. You just, no he's my son. He's a gift. But my mom, you know. At the age of 10 or 12, she just decided I don't want to do his physio anymore. It's too hard on my wrist. Fuck it. But because of that I got very conflicted feelings and I kind of felt that oh, you know, like I'm because of me, this is our family. A few times when my dad was possibly going on strike and I was thinking, that's my health plan. So, you know what happens? We can't pay for my medications out of pocket. I'm going to bankrupt this family. So, bit of that kind of drove me to why I became a productive member of society to be able to support myself (16, 17, 18, 19, 20, 21).

When speaking to CF (RD) positive aspects and meaning and purpose in life, Jake again refers to feeling "lesser than," and sites "striving to show people I'm better than just a sick kid" as a primary motivation. He initially, uses the word "we" not "I" to describe his experience, however, he then acknowledges that this may be his sole perspective. He elaborates that having CF (RD) has caused him to prioritize "what's important … will it bring [him] happiness:"

> We just want to feel like you know, yeah, I might be disabled but I'm capable just like anyone else, and I'm pretty smart and I have a lot to offer so don't just write me off, you know … so that's a major thing, about living with CF, it's almost like you feel lesser than people and you want to prove yourself. You know frequently. At least that's my perspective. Maybe some other people some other people might have come from much healthier households and families and, you know, realize that you just do the best you can and you're great, whereas striving to show people I'm better than just a sick kid … hey, you guys like I just want to be treated like everybody else. Do you know what I mean? And there's so much more to me. Yes, I have CF and it's a big deal. But there's more to me than that … tomorrow might be or next week might be the moment that kills you. If that's an expression that makes sense, like, you never know when your last day will be, so you gotta make sure that you do you prioritize what's important to you. I just decide … will it bring me happiness? Cause if not, if this is my last night on earth, this is not how I want to spend it. This is how I want to spend it (22, 23, 24, 25).

As an adult, Jake now discloses his illness to others to take care of his health. In this sense he has come a long way in integrating a CF (RD) identity, in owning his CF (RD) story. People are "impressed" that he had a lung transplant, a very different experience for him. This seems reparative. CF (RD) is not such a stigmatized "thing" anymore. Whereas when Jake was a child,

he needed to convince others that CF (RD) was not all that he was and therefore chose concealment over disclosure, he now has the self-knowledge and self-awareness that his identity does not limit itself to CF (RD) although it is part of his life:

> Oh, all my close friends, contrary to when I was growing up in high school and elementary school, when I didn't tell anybody I had CF, and it would be like my dirty secret, I tell everyone now. Every friend every acquaintance every co-worker knows I have cystic fibrosis. I actually usually bring it up in conversation when I first meet them and it's mostly to explain to them that hey man, if you got a cold or sore throat or the flu or anything let me know so I can stay away from you. That's all it is, but it's just more and you know the reaction is most of the time they're actually impressed … I've been happily married for 10 years. I've got a career. I've got all sorts of great things. I'm older, it doesn't matter as much as it used to (26, 27, 28, 29).

The integration of a CF (RD) identity began in earnest for Jake while waiting for his double lung transplant. He had been struggling psychologically with fear and anxiety and with existential loneliness, the feeling that he was "living in a bubble … the only person in the world with CF," while waiting for donor lungs (Marseille & Messias, 2020). Drawing upon his proclivity to express himself in writing, and a desire to alleviate his anxiety he decided to connect with like others and join a blog. Whilst this experience initially helped him to feel like he had "a whole community of friends," over time as they passed away, "every death took a toll." Ironically, reaching out to others to assuage his emotional difficulties and loneliness has resulted in a self-imposed interpersonal isolation from those with CF (RD) (van Bruggen et al., 2017):

> Sometimes because you're living with CF you feel like living in a bubble and you don't know anyone else with CF, so it feels like you're the only person in the world with CF …

> When I was waiting for transplant for the two years … I was a mess. I was very scared all the time. I was worried that my condition was going to get worse. I was worried that they wouldn't be able to find lungs in time for me. I was just … anxious all the time. I was just having trouble sleeping … that's when I befriended a whole bunch of CF people online … it was some sort of blogging thing or live journal … and I guess I was starting to come to terms [with the fact] that I've got cystic fibrosis. I'm just going to, you know, I'm just going to whoever wants to read it. Suddenly in the span of a few weeks I had a whole community of friends … we stayed friends maybe five, six years. But overtime things would happen, and they'd pass away … And you know, they say that you think that every time someone passed away from CF, it gets easier. But it doesn't. It gets hard. I go into a black mood … you know, for a few days you're very depressed and anxious … And taking stock. So, it's weird because I know we can't be around each other and stuff, but they still feel like family … we all have common struggles. So, we're like brothers and sisters, you know. So, it just every death took a toll on me. I don't want to sound dramatic, but that's why I don't really want to get to know any other CFers … cause it's just really heart wrenching to lose them again, you know (30, 31, 32, 33, 34, 35, 36, 37, 38, 39).

Jake's impending transplant caused him to struggle with existential death anxiety and eventuated in him "concocting paranoid theories." He at first looked for "hints and clues" in the experience of others who had passed away with the hope of "learning from their mistakes" and thus surviving. "What happened? What did they do wrong?" (40). What helped was a therapist who listened but was frank about "what [was] actually happening" and a girl that he had dated with whom he discussed the physics of death. In both instances Jake felt reassured by scientific explanations:

> The real thing to help there was they put me in touch with a therapist or psychologist … It's hard to explain this but one of the things I guess … when you're waiting for transplant, and you know you're calling the pager number you get to call a hotline to see where you're at in the waiting list and you're not moving for a few months and suddenly you start concocting these paranoid theories … Or you know, the system is rigged against you or something like that … You need someone to … talk you down at least to help hear all your crazy ideas and theories and like, well, no, that's not true. And you know this is what is actually happening ... Like she took the time to listen, but she was also very frank, like she didn't try to like sugar-coat it … and sometimes she was even able to give me specific [scientific] explanations of why things were happening … the reason why you're feeling this fear, your [brain] controls your … And I guess… I'm reassured by science … Something else that helped, ironically enough, it was a girl I was dating. We only [went on] two dates, but … we're talking about death … and she says well you know it's proven scientifically that energy doesn't dissipate, it just changes form … so when you die your soul is going to go somewhere else cause there must be some sort of energy in us, you know, so it's not like you blink out of existence. You're going to either mingle with the Universe or become a star somewhere … it just kind of made me feel reassured like, OK, well this isn't the end if I don't make it through transplant. I die here now. Well, at least we'll see what … the next adventure will be (41, 42, 43, 44, 45, 46).

Finally, based in his experience, Jake has the following recommendations for CF (RD) counsellors/psychotherapists: 1) "be non-judgemental [as this] would help me to talk openly;" 2) "hear me out if I'm spinning out and be frank with me, reflect back the reality/factual evidence;" 3) "explain to me scientifically what is going on in my brain, for example, my [amygdala] is all

fired up and that is why you are feeling fearful;" 4) "have background knowledge of CF;" 5) "recognize that the person with CF who is coming to see you probably has a lot of fear and uncertainty about their future and when their health is going to take a dip;" 6) "I don't need your false empathy … like oh I feel so bad for you … or sit there and tell me that you have had the same experience. It's not at all the same. So, let's keep that in check;" and 7) "genuine and active listening works, for example, you're listening, you're checking things out, you're responding." Jake's last recommendation is mostly directed at CF (RD) doctors: "doctors need to give frank answers, don't sugar coat it" (47, 48, 49, 50, 51, 52, 53, 54, 55, 56). These recommendations have been incorporated into The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

8.3.5 Karen. November 17, 2020

Karen did not volunteer to be a co-facilitator in focus group three (CF 18-30) preferring instead to be "an active participant." She shared in the focus group introductory icebreaker exercise that she was 25, works for the government part time and has been at the Ottawa CF clinic for six years. She "used to be followed at the CF clinic in Toronto." Karen had been diagnosed with CF at 18 months old, her primary languages are French and English, she is living with her parents and is single. She has an undergraduate degree. She identifies as a person with a non-visible illness/disability, stating the following in her response elaboration, "It's a medical condition that another person would not be able to determine by just looking at you. My disease manifests internally primarily, therefore I don't require physical aids." She has had previous counselling/psychotherapy experience, commenting, "I started therapy after having gone through an emergency neurosurgery. Through the process I was diagnosed with ADHD. I now take medication and am thriving!" The fact that Karen has ADHD is important as she is conscientious

about "getting [her] point across" in a way that is explicable, and she references the significant cognitive impact of having CF in terms of time and space, throughout her interview. As example of the former, Karen is conscious of "going off on tangents" and frequently mentions the need to "rein [herself] in." As example of the latter, at the outset of her interview she states, "we have to constantly think in time management and possible scenarios where we may need medical care … that in a way makes us hyper planners and very controlling over our space" (1, 2). Karen's ADHD may factor into her hypervigilance, concerned that she must somehow stay on top of an illness that is fluctuating, non-visible and, to a large extent, uncontrollable (3). Nonetheless, she states that "it is a load that [she] carries willingly … because it's our lives" suggesting existential responsibility (4, 5). Toward the end of her interview, Karen expressed appreciation for the participatory process, for the "respectful space" that had been created which allowed co-researchers to be heard and therefore offer rich feedback that she hopes will help others (6).

Participating in focus group had been a positive experience for Karen who feels that the experience-based knowledge of patients is pivotal to change within systems. She has been helped by therapy to move from a place of anger and hopelessness to an "expanded perspective" regarding how her "disease informs [her] life," which has been "transformational." She is hopeful that the framework will "create a safe environment for patients" to feel that they can also "share [their] piece."

> So, in terms of … just having to be patient centred consulting patients I think that's great, cause I think it speaks too of what we've all been talking about. The only way to work with the disease that's a spectrum is to talk to people who are on that spectrum …experience based knowledge … because that's also how approaches to patients also change and it requires that dialogue … less administrative more grassroots … I must admit I left our

> conversation on such a high cause I think that all of us were not expecting to go as long as we did, but I think also I think the fact that we had so much to share, I think, speaks to the potential of a virtual therapy environment for CF patients … And that's why I very much so have a lot of hope for this research [for this framework] that's being done and the potential for good. Because having been through the process of I feel very angry about my disease and my future prospects, but then also having gone and sought [therapeutic] help to gain an expanded perspective as to how my disease informs my life has very much been a very transformational experience for me. And it's also been a very cathartic one, but more specifically a very forgiving one. So, I am hopeful for other patients who may potentially be hesitant about going to therapy to if the clinic is able to create a safe environment for patients to feel that no matter at what stage you're at, you can share your piece (7, 8, 9, 10, 11).

The importance that Karen places on patients being heard by those who treat them, doctors, nurses, other members of the healthcare team, inclusive of counsellors and psychotherapists, stems from her personal experience. Even though she had been told from a young age that she "was the determinant of how well [her] lungs do" thus becoming her "fiercest advocate" and "master of [her] destiny," she has been met by disbelief regarding her illness from specialists outside CF clinic that undermined her sense of self - efficacy. Karen attributes the "trauma of having to justify [her] illness" while on the neurosurgery ward at The Ottawa Hospital to both the "non-visible nature of CF and the fact that CF is a spectrum with some doctors getting very static in their thinking as to how CF manifests" (12, 13, 14, 15, 16, 17, 18, 19). Karen has been discerning in her interpersonal relationships in terms of letting people in since people do not understand the nuance of her illness and she is reticent to be perceived as "the dying friend" (20, 21, 22, 23, 24, 25, 26, 27, 28). Still,

in these instances the decision to pass as normal has been volitional, the non-visible nature of her illness allowing for choice. Conversely, having that choice taken away, having to fight for CF medications whilst at one's most vulnerable, "triggered a very angry response" and then a "numbing feeling" and in turn a "very very bad depression" (29).

Karen's experiences with her illness, however detrimental, have none the less "fueled [her] sense of meaning and purpose in life and brought positive aspects." For example, "CF has taught [her] the importance of compassion and empathy … that at our core we want to be heard, we want to be seen and we want to feel supported." CF has also "driven [her] to defy ceilings that people have set for people with disabilities and in particular for CFers …whose parents are told you're not going to see your kids grow up" (30, 31, 32). CF has meant that Karen has "matured very quickly," learning to discern when to reach out for support (33). Because of CF, Karen has found meaning in the moment, the joy of being present for her nephew's life and the understanding that pain can exist alongside joy:

> It's the joy that I feel of being able to be present for my nephew's life … that's one of the positive aspects of CF. Because we don't live in the Fantasyland cause some people do. They're like life is sunshine and rainbows. We understand that life comes with its dark patches, but it also comes with the idea of there's still joy to be found in seeking those moments out because as much as pain exists, so can joy and it's just a matter of taking it as it comes and taking it one step at a time (34, 35).

Having shared both her negative and positive CF experiences, Karen spent the remainder of her interview thoughtfully making recommendations to CF counsellors/ psychotherapists and CF doctors, nurses, and all allied health, with the latter centring on integrating mental health into CF clinic. Her recommendations for CF counsellors/ psychotherapists include the following: 1)

"have a balance between the light and the dark …we don't need you to cheer us up … we need you to read the room and keep us moving;" 2) "focus on the tangible components of here's my issue … let's break it down;" 3) "ask how can I support you in this session …because that builds trust;" 4) "understand CF from a variety of standpoints … with as much exposure to the various spectrums of the disease … for example working with patients who are going through transplants;" 5) "in terms of knowledge, understand what we go through." For example, "sit in on clinic appointments to get a feel for what kind of questions we are asked … what pulmonary function tests are … know about medications … how stressful it is to apply for them … our specific treatment regimen." With this knowledge, "from a mental health standpoint you can help us to mitigate the treatment load and practice self-care, for example, saving shows to watch while I do my nebulizer;" 6) during sessions "discern okay this is something that we need to stick on or I think we can move forward. Please do this in a constructive way;" 7) "be very skillful and tactful about transitions and time keeping because … [that] establishes trust;" 8) "be transparent … this is what I mean by that … because as patients we read into everything specialists do." You can "bring in little anecdotes of [your] life … cause that also creates trust;" 9) "respect boundaries …there is a grey area as to where you can push where you cannot. With CFers who've been to hell and back very very recently… they may not be ready to talk;" 10) "please don't put me in a box … understand that a lot of my experiences are influenced by my CF but are not tied to my CF … there [might be] environmental factors leading up to how I'm feeling depressed;" 11) "ideally … have the option of virtual appointments … and help me to work through one thing and then by the end of session have one piece of [relevant] homework to work on;" 12) "CFers have a fear of abandonment … and we don't want to burden people if we decline … understand that working with CFers is going to be emotionally heavy … once you earn our trust we're in it for the long

haul;" 13) regarding "meaning and purpose in life help us to talk about fertility and work through those emotions … do we want to be a mother;" and 14) help us to talk about and work through "how our bodies function … that all could be difficult to talk about without help" (36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 601, 62). Karen's recommendations for CF doctors, nurses, and all allied health inclusive of CF counsellors/ psychotherapists are as follows: 1) "have support in clinic from a mental and emotional side … someone saying this is stressful, that's normal, will be very helpful;" 2) "ensure that the social work/mental health position is full time and not shared between clinics because when they come in and out we start to tune people out;" 3) "operationally, have sessions outside clinic hours … and the option of being able to do group therapy or one on one virtual sessions, and time slots for both;" and 4) "have a structured group format instead of leaving it to us because … meeting other people with CF is weird … we're all a little socially awkward … and we can't hang out offline." With a structured group format "people can find community and get that social connection" (63, 64, 65, 66, 67, 68, 69, 70, 71, 72, 73). These recommendations have been incorporated into The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H). It is worth noting that some of Karen's recommendations are being implemented already, for example, one-to-one sessions are being offered virtually on an ongoing basis.

Finally, regarding feedback and suggestions re: PAR methodology, general comments and dissemination of results, Karen had these closing thoughts: 1) "including patients … doing the focus groups and … interviews are incredibly crucial … it's also important to include the nurse practitioners … they're the ones that are typically fielding our calls … and can provide context from the operational side;" 2) "In terms of patient participation … because of the massive age

range that's in the adult clinic I would be interested in hearing from the different ages;" 3) " the disability community has always been talked about it in stereotypes and rooting [the study/the framework] in experience contextualizes the stereotype … it will also disprove it;" and 4) "It's important to think through the [communication] strategy for dissemination of results … the knowledge mobilization component. I'm a very big supporter of making information accessible to different types of learners … we can infuse some innovation and creativity" (74, 75, 76, 77, 78, 79, 80). It is worth noting that some of Karen's suggestions have been implemented, for example, the inclusion the CF nurse coordinator in the development of the framework. Persons with CF from various age ranges have also been included in the design of our study.

8.3.5 Veronica. November 24, 2020

Veronica did not volunteer to be a co-facilitator in focus group one (CFRD) "because as it is [she] has a hard enough time putting [her] own thoughts and feelings into words." She shared in the focus group introductory icebreaker exercise that she is a "homebody" who loves gardening, crafts and baking and is completing a business diploma during the pandemic. She had been diagnosed with CF at one day old, her primary language is English, she is living with her parents and is single. At the time of the study, Veronica had been 23 and had recently completed an undergraduate degree. In terms of identifying with one of the three groups in this study Veronica marked in only CF 18-30 as she was being monitored for CFRD but did not yet have a confirmed diagnosis. She identifies as a person with a non-visible illness/disability, stating the following in her response elaboration, "Yes, because I am not able to do the same things as a 'normal' individual. Ex: I get sick more often which limits what I can do. Another would be that it would be unwise to become a baker due to the amount of flour that gets inhaled." Being that Veronica loves baking it is poignant that she mentions CF hindering this career aspiration. In fact, finding a

career path that fits with her illness is an ongoing challenge for Veronica which she elaborates upon in her interview. She has had previous counselling/psychotherapy experience, commenting, "I have been receiving counselling for approximately three years." She shares at the outset of her semi-structured interview that she is "busy as the end of the semester is coming up …mainly just projects and one exam." Regarding PAR focus groups, meeting others with CF (RD) and the semi-structured interview Veronica shared the following:

> I'd say by using PAR you're capturing what you need in this study. Focus groups are helpful because someone might say something that then sort of you'll have something to add on, or you might not have thought of or remembered to say it … Yeah, that was definitely a completely different experience for me, cause I've never actually talked to someone else with CF before that point. So, it was a very different and like good experience to see that other people had similar perspectives or experiences to me … And so, it can be helpful. And then also just the individual interviews. Um you can build more on what you wanted to say and there aren't the other people. So, it can be a little more, I guess in-depth or personal. So, you can kind of get both sides of that (1, 2, 3).

To begin, Veronica prefaces many of her comments throughout the interview with some version of, "I'm not the best at explaining things," however, she proves to be very insightful and eloquent. For example, she initially describes her day-to-day life with CF as "not that bad," however, upon reflection, continues that "integrating new treatments can be a little hard … finding the mental space" (4). By mental space she refers to added treatments that can take up more time physically but more importantly can be a cause for worry, "because it … feels like you're getting worse" (5). She surmises that persons with CF "use more energy just in general during the day … so there is the physical energy and the mental energy combined" (6). Mental energy for Veronica

is also expended in the interpersonal realm, the Mitwelt, for example, “worrying about how your family thinks and feels before your own thoughts and feelings” (Marseille & Messias, 2020; van Deurzen, 2012). (7). Being other oriented has been an ongoing issue for Veronica who withheld her struggles “mixing education and CF” from her parents, which she believes contributed to her “burnout” (8, 9, 10).

Veronica discusses the limits that CF has put on her career and travel, friendships, education, and mental health largely due its fluctuating and non-visible nature (11, 12, 13). She attributes her “burnout,” to missing classes, having to catch up, socializing less combined with “pushing the CF side back:” The latter proclivity may be due to a combination of factors including “protecting” her family, denial and wanting to pass as “normal as possible” free from stigma:

> For education, it's been more difficult cause it's definitely in high school and university I was probably only in attendance for 50% of the classes cause yeah, I was just tired or sick … so then I have to catch up on all that stuff which then adds. Just. Stress. I guess also you socialize less because I get sick more so then you can't go out. And I'd say the mix of education and CF were probably the two big contributing factors cause I burnt out in university and third year … In University, I had to go on Home IVs twice … So, I was dealing with the schoolwork and then I couldn't really push things back. Because then it would just cause a lot of stress all at once. Yeah, and then also I think I was also trying to be as I guess normal as possible. So, I was also sort of pushing the CF side back, which yeah, all sort of snowballed into burnout (14, 15).

Veronica refers often to “the problem of having CF” but also “the same life expectations as everyone else to follow the normal life path …. you know go to school, get a job.” After graduating from her university program and prior to COVID she “started applying for work …

purely out of obligation to [her] parents." COVID brought a reprieve, symbolically given her CF, "time to breath," a break from societal expectations. She decided to enroll in an online diploma in business. Throughout she wonders if she "took on too much too soon" as it's "hard to do everything when you don't have your full mental capacity … and feel steadier from a mental health perspective" (16, 17). During COVID Veronica has also been "the healthiest [she] has ever been due to the lack of exposure to germs." However, she observes that "it's a double-edged sword … because it feels great to not be sick all the time, but then I also have to go back to socializing. I'm getting sick again and again" (18). Regarding work and school "people's expectations are greater when you have a non-visible disability … so you look fine. They are only understanding if you bow out to a normal person point" (19, 20). It is notable that Veronica feels compelled to meet career and social expectations and, in most circumstance, chooses to conceal the mental health implications of balancing "all of it with CF," which comes at a great psychological cost.

In terms of "how CF has impacted [her] sense of meaning and purpose in life," Veronica playfully shares, "one positive thing … as an introvert it comes in handy when I want to get out of something." On a more profound note, CF has "made [her] care less about the less important stuff … like getting caught up in other people's drama … and instead focus on the important things … life is short. It makes me want to do the things I wanna do" (21, 22, 23). Here, Veronica exemplifies Frankl's humour and self-detachment and freedom of will, will to meaning, and meaning in life (Block & West, 2013; Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Nochi, 1998). She at first interjects levity to her situation helping her to detach for a moment from the seriousness of her illness. This in turn causes her to reflect upon the perspective that CF has brought into her life, "life is short."

Therapy has also been instrumental in Veronica remaining grounded and gaining perspective. It has helped her to be more comfortable talking about herself and to have more insight into her psychological processes and "have better coping mechanisms:"

> I'd say therapy has definitely made me more comfortable with answering these types of questions. I'd say before therapy I probably wouldn't have even considered joining the study cause it's like Oh my gosh talking about myself … I now have better coping mechanisms and I'm better too at identifying when I'm starting to spiral downwards with either anxiety or depression. It … probably too has helped me sort of get to this point in the semester, despite being that busy (24, 25).

Based in her experience Veronica has the following recommendations for CF (RD) counsellors/ psychotherapists and CF (RD) doctors, nurses, and all allied health, with the latter centring on integrating mental health into CF clinic. Non-judgement is a prevalent theme. Her recommendations for CF (RD) counsellors/ psychotherapists include the following: 1) "for me to talk openly it's important for therapists to be supportive and non-judgemental because if you feel like their questioning what you're saying or the way you're seeing things it can make you shut down;" 2) "some skills that are important for a therapist to have … are probably the ability to ask questions, especially if someone's new to therapy … or they're still not great at understanding what's going on in their head;" 3) "help me to find the words to describe my emotions … and gain insight and what to do with that;" 4) especially when a patient is new, "find one or two topics that they are comfortable with to get the ball rolling conversationally" to build rapport and trust; and 5) have "knowledge of anxiety and depression and techniques to help the patient reduce those or [find] healthy coping mechanisms" (26, 27, 28, 29, 30, 31, 32, 33). Veronica's recommendations for CF (RD) doctors, nurses, and all allied health, inclusive of counsellors/psychotherapists

include: 1) “therapists should have more of a presence in clinic from a younger age to normalize the prevalence of mental health issues in people with CF for both patients and caregivers;” and 2) social workers/mental health should “pop your head in at clinic appointments even though it doesn’t seem like there are issues. Ask, I see you were sick here. How are you doing? Did that impact anything?” (34, 35). The following is Veronica’s observation and recommendation specifically for CF (RD) doctors: “I find doctors super judgemental … it’s like oh you weren’t doing your treatment … but consider that there are mental health issues behind why. There might be underlying causes for my ‘non-compliance’” (36). These recommendations have been incorporated into The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

Finally, regarding feedback and suggestions re: PAR methodology, general comments and dissemination of results, Veronica had these observations/recommendations: 1) “it would be great to share the results of this study with CF patients not just at the Ottawa clinic but other clinics and yes request feedback before finalizing [the framework] just in case something wasn’t fully understood;” 2) regarding dissemination, “I like the idea of both a pamphlet and a written article … because the pamphlet can give a quick overview … and for a more in-depth understanding there’s the journal article;” and 3) “If the article is in a medical journal than doctors may learn more about CF from the patient’s perspective and be less judgemental” (37, 38, 39).

8.4 Section Two: Semi-Structured Interviews Horizontal Analysis

Whilst section one highlighted the phenomenological experience of each of the six co-researchers, Charlene (30), Kyle (47), Alice (25), Jake (39), Karen (25), and Veronica (23), and their observations/recommendations for CF counsellors/psychotherapists/interdisciplinary team members, section two examines the commonalities and differences between them, where present.

When discussing common themes this researcher remains within a narrative format to keep our co-researchers at the heart of their stories and to "convey coherence" in their experience (Seidman, 2019, p. 129).

Semi-structured interviews took place in the month of November 2020 between November 5th and 24th and were organized to fit with co-researchers' work and school schedules. Two co -researchers from each of the three focus groups - CFRD, CF 39 +, CF 18-30 - were interviewed. In terms of personal characteristics, ages of co-researchers fell between 23-47, an age range of 23 years. Two co-researchers, Alice, and Jake had confirmed diagnoses of CFRD whilst one co-researcher, Veronica, had been flagged by the CFRD clinic interdisciplinary team as being at risk for CFRD, and therefore followed for blood sugar levels and other markers that would put her at risk for the disease. In terms of age of diagnosis fully five of our six co-researchers fell in the early diagnosis range, from one week to 18 months old, with one late diagnosis, Kyle, at 9 years of age. Three co-researchers were partnered and three single at the time of this study. All co-researchers had either a college or university degree or in some instances both. All co-researchers identified as a person with a non-visible illness/disability with many of their response elaborations centring on the fact that CF (RD) has a negative impact on their day-to-day level of functioning although it "manifests internally." CF is separately referred to in their responses as an "illness," "medical condition," "disease," and "disability," which may be nomenclature or reflect the spectrum of CF and the extent to which it intercedes in their lives. All co-researchers apart from Jake marked yes to previous counselling/psychotherapy experience, however, we discover in the semi-structured interview that he too had received help from a "therapist or psychologist." Many co-researchers refer to counselling/psychotherapy having helped them at pivotal junctures in their lives, for example, when faced with "systemic issues," regarding relationship issues, "having gone

through an emergency neurosurgery," just prior to lung transplantation and when experiencing burnout at school. Many refer to counselling/psychotherapy as having helped them at a profound psychological level, for example, coping with panic attacks, moving beyond "not feeling good enough" to "a sense of self-worth," finally being able to sit with "negative emotions," moving beyond "paranoid theories," moving from a place of anger and hopelessness to an "expanded perspective" regarding CF, and developing better coping mechanisms to stave off anxiety and depression. It is worth noting, in terms of personal characteristics, that two co-researchers, Kyle and Jake, could "split [their] lives" into "post and pre Trikafta" and "pre- and post-transplant" respectively, using similar descriptors, "a huge game changer" and "life changing," to emphasize the profound impact on the quality of their lives.

Regarding feedback and suggestions re: PAR methodology, general comments and dissemination of results: all co-researchers expressed appreciation for the opportunity to expound upon topics in the semi-structured interview, with Charlene's feedback perhaps summarizing the sentiment of the group, "I was able to … say a lot of the stuff that I didn't want to burden time on with the focus group" (1). Along these lines, according to Veronica, the semi-structured interview allowed for a "more … in-depth or personal" account of her experience (2). Most co-researchers had a positive experience participating in focus groups in that it helped them to feel "less in a vacuum" and gain insight by engaging with like others (3, 4, 5, 6). Participating in focus group felt "life changing" for Alice in part because it helped people to connect as a community, prompted Karen to leave the "conversation on such a high … since all had so much to share … [speaking] to the potential of a virtual therapy environment," Charlene realized that CF "really did impact [her] day-to-day," and hearing others' stories helped Kyle to "[understand the emotional impact of transplantation] and reflect upon his own journey" (7, 8, 9, 10, 11). By contrast, Jake would

participate again albeit with some trepidation as he would have to "bite [his] tongue if there's people in there you might not agree with" (12); in terms of the more general comments regarding PAR methodology, Veronica stated, "by using PAR you're capturing what you need in this study," Kyle had been happy to have Charles, a person with CF, co-facilitate the group because "it made things flow … and feel … more comfortable," and Karen appreciated the participatory process, for the "respectful space" that had been created which allowed co-researchers to be heard and therefore offer rich feedback (13, 14, 15). She added:

> Just having to be patient centred consulting patients I think that's great, cause I think it speaks too of what we've all been talking about. The only way to work with the disease that's a spectrum is to talk to people who are on that spectrum… less administrative more grassroots (16).

All co-researchers agreed to share the framework with others with CF (RD) and request feedback before finalizing it (17). Ideas for disseminating the framework generally distinguished between target groups, patients versus counsellors/psychotherapists and other members of the interdisciplinary team (18, 19, 20, 21, 22, 23, 24, 25, 26, 27).

At first glance Charlene, Kyle, Alice, Jake, Karen, and Veronica seem to have disparate stories. For example: Charlene struggled with individuating from her parents and finding her competence; Kyle has an enduring sense of "not feeling good enough;" Alice is faced with integrating a new CF (RD) identity after a decline in her health; Jake had a difficult upbringing which impacted his sense of self; Karen grapples with ADHD and had to cope with the disbelief of others when on the neurosurgery ward; and Veronica struggles with meeting the "same life expectations as everyone else to follow the normal life path" which led her to concealing her illness and jeopardizing her mental health.

Upon further analysis, there are many commonalities, however, themes which run through every one of our co-researchers' narratives which in some instances intersect and include: 1) **vulnerability versus control:** overcoming vulnerability (mental health issues, the capriciousness of CF(RD)) by gaining a sense of control or mastery over one's life. This theme is consistent with the work of Trandel et al. (2019) who identified feeling in control of one's situation as an existential need to cope with existential distress in those with CF; 2) **concealment versus disclosure:** the decision to either conceal or disclose one's CF (RD) which in part aligns with the degree to which one has integrated a CF (RD) identity; 3) **finding meaning and purpose in life *because of* [emphasis added] CF (RD)**; and 4) **helpful counselling/ psychotherapy experiences** which may not only improve one's mental health and overall outlook but assist with the integration of a CF (RD) identity. Existential and spiritual themes are prevalent throughout with the principle of self – transcendence recurring. For example, some co-researchers explicitly state that they have participated in this study with the hope of helping others. In the following paragraphs I shall highlight these themes in each co-researcher's narrative.

Vulnerability versus control: Charlene felt "probably depressed" at one point in her life when she concluded that she fell behind her peers as a consequence of her illness and "overprotective" parenting. She feared she "didn't have the skills or the opportunities to learn how to be independent … Steady job … school … career." She was also concerned about feeling sick and vulnerable and not getting the support she needed. She had negative experiences with persons and systems assigned to help or in positions of authority which left her feeling hurt and unseen. The way she eventually "turned things around" was to "force [herself]" to change aspects of her life over which she had control unlike her illness. For example, improving her overall health by exercising, learning social skills by volunteering, writing to her MPs to expediate change within

systems, and surrounding herself with a trusted circle of friends/family to be there "in times of need." **Concealment versus disclosure:** Charlene reiterates that having a non-visible illness/disability means that one can control whether to conceal or disclose CF and in what context. As she has intergrated her CF identity she now discloses her CF to others more readily. **Finding meaning and purpose in life *because of* [emphasis added] CF:** CF has allowed Charlene to "let go of things easily" and to "appreciate more every moment." It has made her appreciate that "life is not all positive and perfect" and to embrace challenges as "beautiful." **Helpful counselling/psychotherapy experiences:** Charlene finds a solution-focused approach to counselling/psychotherapy most helpful as it assists her "to plan and better be prepared" (28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44);

Vulnerability versus control/ finding meaning and purpose in life *because of* [emphasis added] CF: Kyle has struggled with CF to the point of being on the lung transplant list and, prior to this study, placed on Trikafta on compassionate grounds. Kyle benefits from knowledge transmission through stories and believes that others would too to prepare for the progression of the illness. Along these lines, hearing others' stories during focus group helped Kyle to reflect upon his own transplant journey and invoke some sense of control, "okay, I gotta fight for that not to happen to me." Today, Kyle is enrolled in a medical program in part to learn about phage therapy, which "may help those with CF on a case-by-case basis with drug resistant infections." This is noteworthy because learning about phage therapy likely gives Kyle a sense of mastery over CF and touches on the principle of self-transcendence, helping others to avoid the same fate (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014). He states early in his interview that learning about phages "gives him a sense of purpose and meaning in life." **Concealment versus disclosure:** "Not feeling good enough" is an underlying psychological and

existential concern for Kyle, which translated to concealing his CF "while growing up" and any mental health issues from family in part to avoid stigma. **Helpful counselling/psychotherapy experiences:** Talking about his experiences "more openly and freely" with a counsellor/psychotherapist has helped Kyle to let go of "not feeling good enough for certain aspects in life like relationships" and instead have "a sense of self-worth." Being in psychotherapy has also helped Kyle to integrate a CF identity, "whereas before [he] was never comfortable talking to anybody … now sometimes [he] feels bad about talking about it too much (45, 46, 47, 48, 49, 50, 51, 52);"

Vulnerability versus control/ Concealment versus disclosure: Alice is adjusting to a decline in her health these last three years, which psychologically can feel like "a pretty big mental battle" and "really difficult especially when at the bottom of it." When her health took a turn for the worse her relationship to CF (RD) and her sense of self changed, for the first time experiencing her vulnerability. Alice reflects upon how COVID has exacerbated her experience of feeling other than, since "most decisions around [her] household are based around keeping [her] safe … which is sometimes a difficult burden." In her youth, Alice "pushed past CF" by engaging in sports and other activities and now life "is a little slower … a little bit more restrictive." A few years ago, feeling uncertain due to the downturn in her health, Alice kept her CF (RD) concealed from work colleagues. Consequently, she faced "the judgements and assumptions of others" and was eventually let go. A turning point occurred when she filed a "Canadian Human Rights complaint … and received a settlement for wrongful termination based on [her] disability," thus feeling empowered. Today, Alice asks herself regarding her health, "Did I somehow along the way stop caring for myself? … Can I be back there? What the heck is it going to take for me to get there?" This sense of control over one's health is instilled institutionally and has been internalized by Alice

(Cystic Fibrosis Foundation, n.d.). It reflects her confrontation with the existential themes of life and death, responsibility, accountability, uncertainty, guilt, and the I-am of identity (Marseille & Messias, 2020; van Bruggen et al., 2017; Yalom, 1980). **Finding meaning and purpose in life *because of* [emphasis added] CF (RD):** When Alice was younger, she had found "a sense of meaning and purpose" by telling her story at fundraising events. Today, she is engaged in this study to "get the word out" about mental health and CF (RD). In both instances, Alice exemplifies Frankl's principle of self-transcendence (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014). **Helpful counselling/psychotherapy experiences:** Counselling/psychotherapy is helping Alice to integrate a CF (RD) identity inclusive of her new state of health. Amongst other benefits, engaging in therapy is helping to "lift a weight off [her] shoulders" (53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66);

Vulnerability versus control/concealment versus disclosure/finding meaning and purpose in life *because of* [emphasis added] CF (RD): At an early age, Jake felt "ashamed of having cystic fibrosis," in part due to his mother's negative attitude toward his illness. Throughout his childhood he chose concealment over disclosure because he "didn't want to be judged based on [his] illness" and just wanted to be treated "like everyone else … I might be disabled but I'm capable." Jake felt driven to become a contributing member of society to offset feeling like a "burden" and, when speaking to CF (RD) meaning and purpose in life, refers to feeling "lesser than," and "striving to show people I'm better than just a sick kid" as a primary motivation. Jake's story is replete with feeling vulnerable – struggling with declining health, psychologically, with existential loneliness and death anxiety - and trying to gain a sense of mastery. For example, leading up to transplant he felt less in control of his health and began struggling psychologically with fear and anxiety and with existential loneliness, the feeling that he was "living in a bubble …

the only person in the world with CF" (Marseille & Messias, 2020). To vanquish his discomfort, he joined a blog to connect with others with CF (RD) awaiting transplant. Even when one by one his friends passed away, Jake looked for "hints and clues" - "What happened? What did they do wrong?" - with the hope of "learning from their mistakes," and thus surviving. **Helpful counselling/psychotherapy experiences:** What helped was a therapist who listened but was frank and assisted Jake to confront his fears through a scientific lens. Today, CF (RD) is no longer Jake's sole identity but a part of his story. He now discloses his illness to others to take care of his health. CF is not such a stigmatized "thing" anymore (67, 68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79, 80, 81, 82, 83, 84, 85, 86, 87, 88, 89, 90, 91);

Vulnerability versus control/ concealment versus disclosure/ finding meaning and purpose in life *because of* [emphasis added] CF: Karen has CF and ADHD, and their combined cognitive impact is apparent throughout her interview. For example, her ADHD may factor into her hypervigilance, and becoming a "hyper-planner," attempting to have control over an illness that is fluctuating, non-visible and, to a large extent, uncontainable. Fending for oneself had been reinforced from a young age when Karen was told that she "was the determinant of how well [her] lungs do" thus becoming her "fiercest advocate" and "master of [her] destiny." This sense of mastery was challenged on the neurosurgery ward when she was met with disbelief regarding her CF and had to fight to receive the care that she required. While she had been judicious about disclosing her CF in interpersonal relationships, in these instances the decision to pass as normal had been volitional, whereas having that choice taken away, having to fight for CF medications whilst at one's most vulnerable, triggered a "very very bad depression." Karen's experiences with her illness, however detrimental, have none the less "fueled [her] sense of meaning and purpose in life and brought positive aspects." For example, CF has meant that she has "matured very

quickly," and it "has taught [her] the importance of compassion and empathy … that at our core we want to be heard, we want to be seen and we want to feel supported." CF has also "driven [her] to defy ceilings set for people with disabilities," and enabled her to find meaning in the moment, that pain can exist alongside joy. **Helpful counselling/psychotherapy experiences:** To mitigate her depression Karen participated in psychotherapy which helped her to move from a place of anger and hopelessness to an "expanded perspective" regarding how her "disease informs [her] life," which has been "transformational." Karen has integrated her CF identity along with her ADHD and, like Alice, explicitly states that she is participating in this study "for the benefit of others" thus exhibiting self-transcendence (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014). (92, 93, 94, 95, 96, 97, 98, 99, 100, 101, 102, 103, 104, 105, 106);

Vulnerability versus control: Veronica has the insight that CF takes up both "physical … and mental energy," especially when new treatments are added which can be cause for worry, "because it … feels like you're getting worse." Mental energy is also expended in the interpersonal realm, the Mitwelt, for example, "worrying about how your family thinks and feels before your own thoughts and feelings" (Marseille & Messias, 2020; van Deurzen, 2012). Veronica refers often to "the problem of having CF" but also "the same life expectations as everyone else to follow the normal life path." She ceases on the opportunity that COVID provides, a viable exculpation from societal expectations, to quit her job and enroll in an online diploma in business thus gaining a measure of control over her life. **Concealment versus disclosure:** Veronica suffered from "burnout" in university for a compilation of reasons including missing classes due to the capriciousness of CF, trying to "catch up," and all the while trying to pass as "normal as possible" free from stigma. She chose concealment in part because she had not yet integrated a CF identity. **Finding meaning and purpose in life *because of* [emphasis added] CF:** In terms of "how CF

[impacts her] sense of meaning and purpose in life," Veronica at first jests that "as an introvert it comes in handy when I want to get out of something." More profoundly, CF has "made [her] … focus on the more important things … life is short." Here, Veronica employs humour to detach from her suffering and then reflect upon the perspective that CF brings. In so doing she exemplifies Frankl's humour and self-detachment (Block & West, 2013; Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Nochi, 1998). **Helpful counselling/psychotherapy experiences:** Therapy has helped Veronica feel more comfortable talking about herself, gain insight into her psychological processes and remain grounded during her studies. Like Kyle, she also shares that it has helped her to "feel more open about [her] CF … although it depends if [she] feels safe" (107, 108, 109, 110, 111, 112, 113, 114, 115, 116, 117, 118, 119, 120, 121).

Finally, co-researchers were very thoughtful in their observations and recommendations for CF (RD) counsellors/psychotherapists and CF (RD) doctors, nurses, and all allied health, based upon their experiences. Most co-researchers centre their recommendations for CF (RD) counsellors/psychotherapists in three areas: attitudes, knowledge, and skills. In terms of attitudes, an importance is placed on creating an atmosphere of trust, which includes non-judgement, and transparency to be able to talk openly. This is particularly important for those with CF (RD) who "have a fear of abandonment," "don't want to burden people if [they] decline," and are reticent for people to see them when they are "at the bottom of it" or at their most vulnerable. Along these lines, empathy is a valued attitude/skill, however, "false empathy" is not. Once an atmosphere of trust is created, according to Karen, "[they're] in it for the long haul." In terms of knowledge, most co-researchers stress the importance of understanding chronic illness and CF (RD) in particular. Regarding knowledge of CF (RD), it is important to understand that it is a spectrum and to have exposure to the various aspects of the illness, for example, patients transitioning from CHEO or

about to undergo lung transplantation. It is important to attend CF clinic appointments and understand treatment regimens and medication procurement which can be very stressful. Understanding treatment regimens is important because from a "mental health standpoint [counsellors/psychotherapists] can help to mitigate the treatment load and [teach patients] to practice self-care." Along these lines, it is imperative to understand the mental health aspects of CF (RD), "that working with CFers is going to be emotionally heavy," and that everyone is "grappling with a big underlying issue." It is imperative to not assume that "just because someone appears to be healthy it doesn't mean that they aren't suffering from a mental health perspective." Notwithstanding, it is important to meet each patient where they are at "because they all have … different experiences and different needs and are at different stages." As Karen eloquently stated, "don't put me in a box" because mental health may be impacted by environmental factors not just CF. In terms of skills, it is important that counsellors/psychotherapists not only have "knowledge of anxiety and depression" as it relates to CF (RD) but also "techniques to help the patient reduce those or [find] healthy coping mechanisms." At the outset of sessions, it would be helpful to begin with a grounding exercise "which is calming" and "allows for clear thinking." Many skills are important including goal setting, asking the right questions to facilitate insight, respecting boundaries by knowing where to "push [on a topic] and where you cannot," being masterful with transitions, providing tangible and relevant resources to carry over learning and all the while "[having] a balance between the light and the dark." Unique responses include the preference for different psychotherapeutic styles, for example, solution-focused therapy or having a scientific fact-based approach. Sharing the stories of other CF (RD) patients can also help to integrate the mental health aspect of the illness, according to Kyle. Finally, it is important to "have some sort of existential discussion on what CF means" as it "touches so much on death and mortality," "fear

and uncertainty" and "meaning and purpose in life." Recommendations for CF (RD) doctors, nurses, and all allied health, include ensuring "support in clinic from a mental and emotional side." Along these lines, Veronica suggests "therapists should have more of a presence in clinic from a younger age to normalize the prevalence of mental health issues in people with CF for both patients and caregivers." In general, it is recommended that there be a synergy between mental health and the entire interdisciplinary team. Some recommendations underscore the necessity for flexibility in modalities – individual or group therapy, virtual or in person sessions. Veronica has a last word for CF (RD) doctors: "I find doctors super judgemental … consider that there are mental health issues … there might be underlying causes for my 'non-compliance'" (122, 123, 124, 125, 126, 127, 128, 129, 130, 131, 132, 133, 134, 135, 136, 137, 138, 139, 140, 141, 142, 143, 144, 145, 146, 147, 148, 149, 150, 151, 152, 153, 154, 155, 156). These recommendations have been incorporated into The Patient – Centred Framework for Counselling and Psychotherapy for Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (Appendix H).

Chapter 9: Discussion

The purpose of this thesis study has been to answer the research question: what would constitute a patient-centred framework for counselling and psychotherapy with persons with a non-visible illness/disability: cystic fibrosis. The result is a framework that exists and is embodied by co-researchers' life history. In discerning their needs regarding counselling and psychotherapy we have delved into their life stories, their experiences, and problems with CF day-to-day, their experience of having a progressive and/or acquired non-visible illness/disability and how their illness has impacted their sense of meaning and purpose in life. We have asked our co-researchers to expound upon the necessary counsellor/psychotherapist attitudes, knowledge, and skills based in their personal understandings. Focus groups and semi-structured interviews provided an opportunity for those formerly isolated to connect as a community and then expound upon aspects of their lives yielding previously indiscernible themes, for example, vulnerability versus control. Integrating the feedback of key stakeholders – CF interdisciplinary team members and CF patients-added a breadth and depth of views culminating in a valuable framework for counsellors and psychotherapists, as well as interdisciplinary team members.

A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis exemplifies the concepts of post-structural disability theory. Throughout, persons with CF ask for a nuanced understanding of their experience and identity. They ask to be recognized as bi-abled, both able and disabled, depending upon where they are on the spectrum of CF, "don't put me in a box" (Valeras, 2010). They are willing to identify with CF so long as it is not totalizing of their identity and that we recognize "they are persons first … there is more to [them] than CF." Along these lines they implore us to "remind [them] that CF is not who [they] are." In that they have a non-visible illness/disability, persons

with CF require that we believe that their struggles are real, "physical health doesn't necessarily reflect mental health and vice versa." They ask that we dig deeper when they say they are "fine" as they are "used to putting up a front" in part due to the "burden complex." They have struggled their whole lives to be seen and heard and for their mental health to be acknowledged, while protecting loved ones and themselves. They ask that we recognize that CF and mental health - anxiety and depression and trauma - "go hand in hand." Living with a chronic and life limiting illness most certainly affects their quality-of-life day to day and their mental health and physical health exist in a circular loop, impacting one another. Throughout the framework persons with CF beseech us to be collaborative, "non-hierarchical, non-judgmental, establish a friendly but professional connection, stand beside [them] when things get tough." In their note to the CF clinic team, they again ask for nonjudgement, to "understand that there may be underlying causes to [their] 'non-compliance.'" They do not want to be treated less than. Instead, they want to be acknowledged for their expert voices, "we're a different kind of sick … we have been living with [CF] our whole lives." The word "dark" is stated five times in the framework – "have a balance between the light and dark," "sometimes we are a dark disease," "we go to dark places," "eventually the lines will need to move to delve into the touchy areas, the dark stuff," "meet us where we are at no matter how uncomfortable, no matter how dark" – which is unsurprising considering co-researchers employ this metaphor more often than any other when describing their experiences throughout the study. The use of metaphor is helpful to make sense of and integrate one's experience (Deng et al., 2021). Here persons with CF are communicating that their illness is "dark," that they are struggling with death as an existential concern and want us to "walk beside [them]" (van Bruggen et al., 2017). In the same vein, they want us to "prepare [them] … to talk about the potential progression of CF, even lung transplant … and have some sort of existential

discussion on what CF means/the meaning of life as CF touches on death and mortality." In referring to meaning in life we are reminded of the principles of Viktor Frankl (Frankl, 1963, 1963/2006, 1967, 1975, 1986, 1997, 2014; Frankl et al., 2010). In the face of existential concerns, death, and mortality, meaning making and purpose in life may mitigate negative emotional states associated with having a progressive and/or acquired non-visible illness/disability and have psychological and health related benefits (Canda, 2001; Dezutter et al., 2015; Graham et al., 2008; Hoppe, 2013; Mueller et al., 2020; Patterson & Staton, 2009; Psarra & Kleftaras, 2013; Smith & Zautra, 2004; Varilek & Isaacson, 2020; Warnecke, 2017; Wong, 2010).

> Frankl held the conviction that, "meaning making can be found in life literally up to the last moment, up to the last breath, in the face of death" (51, p.76). He suggested that finding meaning in one's suffering created an optimistic shift that could "transform despair into triumph" (51, p ix) (Brietbart et al., 2004, p. 370).

Finally, we see a resurgence of the importance of community as a counterpoint to social isolation. Persons with CF are asking for a structured online group "to find community and social connection." This once again calls to mind the sagacious words of Henri Nouwen, "we want to be people who know what it is to belong somewhere. There is somewhere that is home. There is a place where I am well- held, well -embraced, and well-loved" (Lazarus, 2021, p. 83). In that the idea of PAR is to stop telling stories about people, to honour those who have offered up their voices, herewith is the framework in their own words:

A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis

Preamble:

Every patient and member of the CF interdisciplinary team have the right to be treated with courtesy and respect and in a way that fully recognizes their inherent dignity, worth and individuality, regardless of their race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability.[6]

Counsellor Attitude:

- It is important to have full trust in you. To build trust and a therapeutic alliance:
- Please be empathetic, genuine, supportive, sincere, kind and easy to talk to. Establish a professional but friendly connection. A sense of humour, where appropriate, is an asset;
- Be non-hierarchical (walk beside me). Be open-minded and non-judgmental (even non-verbally);
- Practice active listening, validate my feelings, recall accurate details of my story;
- Establish trust by asking me what I need to feel supported;
- Be transparent and practice skillful self-disclosure. For example, bringing in your own life experiences when I'm feeling insecure makes the session more personal for me. Please don't assume that you know how I am feeling or share at moments when we're trying to explain, when it's better to listen and understand;
- Be tactful, gentle, and respectful with time keeping and transitions. For example, you might say, "I don't want to interrupt your flow, but the session is ending;"

[6] The preamble has been adapted from the Ontario Residents' Bill of Rights, embedded in the Fixing Long-Term Care Act (FLTCA), 2021 and accompanying Regulations (O.Reg. 246/22) www.ontarc.com

- Be supportive of me in clinic, an ally when I am feeling judged for not being perfect with my treatment protocols;
- Look at me not just as a disease but as a human being. Understand that there's an overarching theme of CF, but also wanting to feel normal. There is more to me than CF: remind me that CF is not who I am;
- Have a balance between the light and the dark. Have a thick skin because sometimes we are a dark disease, and we go to dark places, and I might lash out at you because I'm in pain. It's not a personal attack;
- It is important to be able to see you within a reasonable time. Be accessible and ensure that there is a structure for follow up, that I don't fall through the cracks;
- Respect boundaries. Let us know when you are available and be there if we need you to the extent that we need you;
- I need you to not overstep but also to know that you won't leave. I don't want to be abandoned. We need a counsellor who is comfortable to stand beside us when CF gets tough;
- Once you earn our trust, we are in it for the long haul.

Counsellor Knowledge:

- Please understand that CF and mental health go hand in hand. We are dealing with a chronic and possibly life limiting illness that affects our quality-of-life day to day. If we are not feeling well emotionally this could affect our motivation for treatments and then our overall health might decline;
- Please have knowledge of anxiety and depression and trauma. Bad episodes of hemoptysis, difficult acute care experiences, transplants, losing others to CF and parenting a child with

CF can cause trauma and trigger PTSD. Help us to develop healthy coping mechanisms and have knowledge of various techniques to help us to do so;

- Understand our specific treatment regime and how we can mitigate the treatment load from a mental health standpoint;
- Know more about CF than what Wikipedia tells you. I want somebody who's passionate about CF - or understands about mental health and chronic illness;
- Have knowledge that CF is a spectrum-it affects everybody differently and sometimes where you are on the spectrum changes day to day. Have background knowledge of CF from a variety of standpoints and real experience/exposure;
- Take our lead in terms of where we are on the spectrum. Be cognizant that we're knowledgeable as a patient group about what is affecting us. We're a different kind of sick - we're the experts on CF as we have been living with it our whole lives;
- Have a base level knowledge of our day-to-day routines and stressors, the struggles we go through, the medical and financial components that come with CF: for example, understand that CF is emotionally heavy, that we may experience loss when our health declines, the medications we are taking (interactions and the long-term effects), our treatment protocols, the stressful bureaucracy and paperwork/applications for medications;
- Sitting in on clinic appointments to get a sense of what we face and what questions we are asked regularly would be an asset as well as joining in CF Canada events to meet with families;
- Understand that physical health does not necessarily reflect mental health and vice versa. I can look relatively fine but be struggling from a mental health perspective;

- It's important for a counsellor who deals with the CF population to not take it at our word that we're fine because we're used to putting up a front to be strong for others. Be aware of the burden complex: I don't want to burden other people. I need to learn to ask for help;
- You need to have a keen understanding that carrying a lot of this can be very numbing emotionally;
- Appreciate that we are all persons first/we are so many other things -husbands, wives, partners, parents, students, and full or part time workers. Having to juggle all these roles with treatments/being sick sometimes/not feeling like we are good enough in any of these roles can mean that feeling mentally exhausted is often part of our day to day life;
- Don't put me in a box. Understand that my mental health may be impacted by environmental factors not just my CF. Recognize that, depending on where we are on the spectrum of CF, we may have various levels of mental health concerns and require different levels of support. I don't want to be treated sicker than I am.

Counsellor Skills:

- As my counsellor/therapist know that every person with CF has different experiences, different needs and are at different stages. Please focus on whatever aspect of our life we need help with. I don't want to only focus on CF;
- When we're new to therapy, ask questions to get us thinking. Begin by focusing on topics that we are comfortable with to build rapport and trust. Also, normalize seeing a therapist and, if appropriate, give examples of what others with CF are up against that might resonate;

- Begin with a grounding exercise to help us to transition into sessions and hone this skill for when we need it (when overwhelmed and stressed). Mindfulness exercises at the beginning of sessions really make a difference;
- Ask what matters to me, what I'm bringing in today to talk about. Help break things down within the session to tangible components to work on. Help with short- and long-term goal setting. The goal of the therapy and the process must be established at the beginning to avoid confusion or expectations. Let's end the session on a positive note, and focus on what we can work on next session;
- Have a personalized approach (to meet my personality type, what coping mechanisms work for me and to get to know how I like to be nudged and supported). My ideal session: this is how my brain works, this is what I need and the counsellor remembering the micro details;
- Ask the right questions to help us to communicate/put our thoughts and feelings into words and be honest with ourselves, so that we can gain a deeper self-awareness (light bulb moments). I'm "fine" as a default: I need someone to pierce through that. Create a safe space for me to learn how to sit with my deep/hard emotions and know that I'm going to be okay. Where we have trouble finding the words to express our feelings, maybe have a visual chart that breaks down the different emotions;
- Challenge us. Teach me different skills and coping strategies. Point out patterns, touch back on some of the things discussed as a reminder, give concrete feedback about my progress, and help me to grow from each therapeutic experience. What makes a session sparkling is when I feel empowered/ I know I've made progress & carried over the skills that I've learned;

- Engage in a conversation/a dialogue with me: pushing on certain issues, letting others go- I don't want to spin around in my own problems. I want to leave with a bit more clarity;
- Hear me out and then be frank, sometimes it's helpful to provide factual science-based information to reassure me when I'm spinning out;
- I need boundaries to be an ongoing conversation: when to push and not push knowing that eventually the lines will need to move to delve into the touchy areas, the dark stuff. It's helpful to have a counsellor where you're forced to face those harder points that you were afraid of or weren't aware of -we have a lot of fear and anxiety about the future and have to face a lot of difficult issues;
- Help us to work through emotions regarding reproduction, fertility, and how our body functions. I go to a therapist to guide me, to be present with me when I'm sick and to talk about the uncomfortable side of CF. Please do not force positivity but meet us where we are at no matter how uncomfortable, no matter how dark;
- It's okay to have some sort of existential discussion with me, where appropriate, on what CF means/the meaning of life as CF touches on death and mortality;
- In the social media era, getting in touch with others with CF (or parents of CFers) can give us a sense of belonging to a community and a purpose. It can also mean that we don't cultivate who we are without CF. This can lead to a real identity crisis as many of us now have access to modulators and can lead a more "normal" life. Please help us to navigate through this;
- Keep it grounded. I don't need a hero complex. We don't need false empathy or fake validation of our strengths. I need: that's a lot to carry, what do you need to do to self-care;

- Listen to my needs and where I'm at. Don't push your opinion on me about what I should do or how I should take care of myself-let that be a joint endeavor;
- Because lessons don't only happen in the therapy room, provide me with tangible resources to be able to practice, for example, book recommendations and relevant take aways/homework exercises. I need a strategy to practice something: I need that as something to hold onto;
- Sometimes we need a structured approach, an empathetic solution focused action plan, as opposed to just listening. For example, guide us and connect us to the right supports and resources for our situation. Be aware of services and reassure me that it's okay to use them;
- When we ask, or where it is necessary, communicate with our CF medical team regarding our mental health. It's important for our therapist to help interpret our intentions and feelings when we don't always have the voice to do it ourselves. Help advocate for our mental health and concerns, because mental health and physical health are very linked, but it does unfortunately happen that medical help doesn't always factor in our mental health or emotional perspective;
- If possible, provide not just talk therapy but look at creative options that resonate with me to deal with things.

A Note to our CF Clinic Team:

- Please normalize and integrate mental health by making it part of your check list. For example, if you see that I'm sick you can ask, "with everything going on how is your mental health?" If I have a mental health diagnosis, you can ask, how is this effecting your anxiety or depression or --------? Please wait to hear the answer;

- Even if I appear to be doing okay ask how I am coping, nonetheless. Open ended questions are best. For example, you can ask, “is there anything you would like to discuss today?” Please don’t assume that if someone seems physically okay, they’re mentally doing okay;
- Please take the knowledge and exposure learned from having treated so many as precedent to inform my case. Also understand that each CF patient is unique;
- Please understand that there may be underlying causes to my “non-compliance.” Instead of judging or telling me what I should do, create a safe space, listen to my needs and where I’m at, ask questions, and give me time to respond. Walk beside me. Let’s collaboratively come up with a plan that works over time;
- In terms of asking questions, please bring in a mental health lens to how questions are asked. This begins by letting me walk you through my thought process and circumstances and then meeting me there and collaboratively discussing treatment options. For example, you can ask, “are there any side effects to your medications that impact your willingness to take them? If so, what would work moving forward?” A mental health lens allows for personalized care and reinforces patient ownership;
- The CF care team has pretty good cohesion and follow up. Please ensure that there is feedback/follow up even if the situation seems non-urgent. What I want to avoid is you not doing anything because I’m not sick enough. Please follow up/check in sooner, re-evaluate as my health evolves, and be transparent about where the process is at. Sometimes we just want to know that there has been a step toward something;
- It would be helpful if when a mistake is made, when something is missed, that this is acknowledged, and we talk about it openly. Otherwise, it feels like gaslighting with the event remembered as a trauma;

- Prepare us. Talk about the potential progression of CF, even lung transplant. This might help us to be more vigilant about our care, and engage in present and future planning;
- Please ensure that there is synergy between our CF clinic doctors, nurses and social work/mental health. Social work/mental health should be as integral to the health care team as our CFRD nurse. Refer us when we ask, when we're having a hard time, when we're about to have a transplant and when we transition to adult clinic;
- Ideally, the social work/mental health position should be full time and not shared with other clinics. Social work/mental health should provide a continuous program, ongoing support geared toward patient need rather than a set number of sessions. The therapy must be available as long as the patient needs it or have a plan to transition to another qualified professional. Where there is an intern assigned, please ensure that they have the experience, training and supervision to provide competent counselling/psychotherapy services;
- Where social work/mental health is involved, we should be given options, for example, individual or group therapy, virtual or in person sessions, sessions outside of clinic hours. Groups should be run by social work/mental health, and they should be structured. Groups might be helpful to find community and social connection;
- There should be some sort of "therapy onboarding" for both patients and social work/mental health, for example, a Cheat Sheet about the common issues we are dealing with/the BIG themes. This will be validating for patients and informative for all.

Patient Role:

- It is important that we as patients are engaged in counselling and that we contribute to the process for it to work;

- Although it could be difficult to express mental health problems and concerns our role is to speak up and be transparent. Our medical team and social work/mental health can't help if they don't know that something is wrong;
- We need to keep in mind that this is a collaborative process, with the goal of finding the best possible treatment plan. Our role is to express what we're feeling and thinking, to ask questions and to voice when we feel discomfort;
- It is important to understand that our CF team may have limits to what they can do to help, that they can't work miracles;
- Patients have a responsibility to consider our CF team, who also have everyday issues and struggles.

Chapter 10: Conclusion

10.1 Challenges and Limitations of this Study

Acknowledged challenges and limitations of this study include: 1) the difficulty of a university researcher realistically entering a community and creating respectful and collaborative relationships. To this end, great care has been taken to reflect upon process, checking in with co-researchers on a regular basis to ensure that we are communicating effectively and collaboratively working toward the intended goal (Bond, 2004; Kidd & Kral, 2005; Nordentoft & Kappel, 2011; Owen, 2001; Read & Maslin-Prothero, 2011; Smith, Bratini, Chambers, Jensen, and Romero, 2010; Tee & Lathlean, 2004); 2) "designing a plane while flying it," or sharing power when one is used to working independently (Smith, Bratini et al., 2010, p. 409). In PAR, researchers are embedded with others and it takes great skill to know how to remain part of and apart from at the same time, to remain optimally effective. To this end, this researcher has sought supervision from my thesis director to responsibly navigate this space; 3) PAR projects can be difficult to manage in terms of the various co-researchers and stakeholders, multiple sequences, and time frame (Kidd & Kral, 2005; Smith, Bratini, et al., 2010). While indeed time consuming, this researcher is very grateful to have had the cooperation of all parties to have been able to complete this project on time; and 4) each PAR study is idiosyncratic, yielding rich findings, however, generalizability may be problematical due to the difference in target groups and the specificity of methodological design. PAR studies instead build upon one another in terms of adding dimension to an issue and in learning about research processes meaningful to co-researchers (Kidd & Kral, 2005; Smith, Bratini, et al., 2010).

10.2 Acknowledged Strengths of this Study

Acknowledged strengths of this study include: 1) in total 30 stakeholders (n=30)

comprising CF co-researchers, CF clinic patients, and CF interdisciplinary team members, developed and agreed upon the Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis despite individual diversity across many variables, which may lend credence to its practicability (Braun & Clarke, 2006, 2012); 2) being that co-researchers have been integrally involved in the design and implementation of the study and the development and dissemination of the framework it is likely that it is meaningful and relevant to their needs (Bayliss et al., 2008; Bergold & Thomas, 2012; Deegan, 2005; Minihan et al., 2004; Minihan et al., 2011; Riecken et al., 2005; Street et al., 2008); 3) we had a 95% retention rate amongst co-researchers over the course of this two year study, with many referring to being in the focus groups as a positive experience, "a game changer." This may speak to the sustainability of a PAR project; 4) We have strived to meet the criteria for validity in IPA by applying the four broad based principles for assessing the quality of qualitative research-sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance - as well as the independent audit as put forward by Yin (1989) (Smith et al., 2012) and 5) Validity in PAR centres on triangulation and transactional validity, which can be achieved through member checking. Triangulation is threefold: using multiple perspectives, face validity to participants (the extent to which the project is viewed as covering the concept it purports to measure) and catalytic validity (the extent to which the participatory process catalyzes elements for change) (Baum et al., 2006; Bergold & Thomas, 2012; Caretta & Pérez, 2019; Cook, 2012; Kidd & Kral, 2005; Macdonald, 2012; Reason & Bradbury, 2001; Smith, Rosenzweig, et al., 2010). Being that we have incorporated multiple perspectives, co-researchers agree that "by using PAR [we're] capturing what [we] need in this study" and the fact that the framework is being implemented in our Ottawa Hospital Adult Cystic Fibrosis Clinic to improve the way we address

the mental health needs of our patients there is a probability that we have met the criteria for triangulation. Transactional validity was established by co-researchers and stakeholders when they checked the framework for accuracy and resonance with their experience and their feedback eventuated in the final version (Caretta & Pérez, 2019).

10.3 Clinical and Theoretical Importance/Practical Implications/Next Steps

This study stands at the juncture of disability studies, PAR, and counselling and psychotherapy research. It fills a gap in the research literature for PAR in the field of counselling and psychotherapy, particularly with persons with CF. It has empowered persons with a progressive and/or acquired non-visible illness/disability who have been traditionally at the receiving end of research, counselling, and psychotherapy, giving voice to their experience and honouring their strengths and abilities to potentiate real change in their lives. By including persons with CF as co-researchers this study offers original insights into their experience in relation to counselling and psychotherapy and provides important practice guidelines, from their perspective, for therapists and interdisciplinary team members who work specifically with this population and perhaps more generally with persons with non-visible illness/disabilities. More broadly, this study raises awareness regarding the lived experience of persons with non-visible illness/disabilities and progressive and/or acquired non-visible illness/disabilities, which has potential for all of society. To understand that there exists a continuum of disabled bodies begets a more compassionate view of all of us as vulnerable, nuanced, dynamic and fully deserved human beings (Bassler, 2014; Davis, 2005; Fukuyama & Sevig; Heine, 2010; Valeras, 2010). We also have learned about the existential and spiritual concerns of those with CF – life and death, responsibility, accountability, uncertainty, guilt and the I-am of identity - and the profound impact of having a life limiting illness/disability on one's sense of meaning and purpose in life. According to Freud (1920, as cited

in Lebigot, 2011), we all know we will die, but we do not believe it because there is no representation of death in the unconscious. For those with CF, death is a reality not just a concept. They are confronted personally with death and witness the death of others with the same illness. Yet, despite CF, co-researchers strive for meaning and purpose in life, find meaning in the moment and demonstrate self- transcendence inclusive of their motivation to participate in this study. This research therefore adds to the body of literature that submits "he who has a *why* to live for can bear with almost any *how"* (word is italicized in original text) (Frankl, 1963/2006, p.76) (Canda, 2001; Dezutter et al., 2015; Graham et al., 2008; Hoppe, 2013; Mueller et al., 2020; Patterson & Staton, 2009; Psarra & Kleftaras, 2013; Smith & Zautra, 2004; Varilek & Isaacson, 2020; Warnecke, 2017; Wong, 2010).

Being that we have learned that those with CF are isolated from one another and have derived a sense of community from participating in focus groups, a next step will likely be offering a structured virtual group platform through the Ottawa Hospital Adult Cystic Fibrosis clinic. Next steps might also include a formal study investigating what impact the patient-centred framework has had on co-researchers' lived experience at clinic appointments. For example, what specific changes if any have they noticed regarding how members of the CF interdisciplinary team address their mental health needs? Co-researchers' feedback would be integrated and addressed constituting a second phase of this quality improvement project. Onboarding of both CF patients/counsellors and psychotherapists has also been requested by co-researchers as has the dissemination of the framework. To fulfill the latter, this researcher has presented our research at The North American Cystic Fibrosis Conference Canadian clinics meeting in Philadelphia, November 2022, with the collaboration of co-researchers. The Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illnes/Disability: Cystic Fibrosis

will also be published in the Christmas 2022 addition of the CF Canada website. Onboarding will be addressed by various means in the new year.

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Notes

Section One: Focus Group Vertical Analysis

Focus Group One

1. Emergent theme: With CF(RD) there is a lot of fatigue, so I am a very big homebody;
2. Emergent theme: Just living day to day with CF(RD) is exhausting;
3. Emergent theme: It's exhausting working a job where you're constantly on your feet every day;
4. Emergent theme: Having CF(RD) sometimes means having to be hospitalized for long periods of time;
5. multiple diagnoses - I stopped taking care of myself as a whole; Emergent theme: You're born with this so you should know how to deal with it but it always throws you a curveball- it's not easy;
6. Emergent Theme: I have CF related diabetes (CFRD) which requires blood sugar checking and insulin injection in addition to my lung therapies;
7. Emergent theme: I have CF(RD) and multiple diagnoses and complications. I do about two hours of treatments a day;
8. Emergent theme: I have CF(RD) and multiple diagnoses - I stopped taking care of myself as a whole;
9. Emergent theme: I've been struggling with treatment burden for a really long time;
10. Emergent theme: Symdeco has been life changing and I and everyone are really happy about that;
11. Emergent theme: I've been struggling with treatment burden for a really long time;
12. Emergent theme: I do multiple lung treatments-my mother helps;
13. Emergent theme: Sometimes I keep my partner up at night when I'm coughing all over the place;
14. Emergent theme: CF is a lonely disease-I've lost friends throughout because it's hard to be present if you're in the hospital or trying to recover;
15. Emergent theme: My inability to open up comes back to a childhood of loneliness and not having meaningful connections/just having doctors in my life and nurses;

16. Emergent theme: I've met really nice people- -all these great nurses made me feel less lonely;
17. Emergent theme: CF has meant that I have meaningful connections and strong bonds with friends and family;
18. Emergent theme: It's about having a smaller circle of people you really trust and that understand;
19. Emergent theme: Due to COVID trying to find a remote job is difficult, and a job with benefits is a pressing matter and adds another layer;
20. Emergent theme: Let's just add to the list things that can do us harm - the anxiety of interacting with people in public has been made worse by COVID;
21. Emergent theme: Lately coughing has been a part of my life and that's a little bit scary with everything going on;
22. Emergent theme: It's been hard to be fully transparent since COVID- it's not easy to be friends with someone when you can't see them;
23. Emergent theme: The fertility clinic said because of COVID we can't help you when you're at risk;
24. Emergent theme: My illness is invisible, but people think we're sick during COVID because they don't know the context;
25. Emergent theme: I worked a full-time job before COVID which I haven't been super bored about;
26. Emergent theme: I was also working before COVID and then I wasn't able to and went back to school -fatigue makes it hard to manage things;
27. Emergent theme: COVID has meant that I am the healthiest I have ever been because I'm not interacting with people;
28. Emergent theme: If that mental health piece is overlooked, then your physical health is going to go down;
29. Emergent theme: It's damned kind of either way - mental health and physical health are connected in CF;
30. Emergent theme: It's this double-edged sword-you need to get out of bed to do your treatments, but your mind is making you feel heavy on top of CF;

31. Emergent theme: Stigma, CF and mental health - people think you've had that your whole life you should be used to it but it's been a burden;
32. Emergent theme: The shame part of CF - it's something that we're born with so we're supposed to be experts but it's crushing;
33. Emergent theme: The fertility clinic said because of COVID we can't help you when you're at risk;
34. Emergent theme: I'm mad at the government - they're making me choose between my health (a new CF drug) and having a baby;
35. Emergent theme: It was a grieving process to decide to foster children instead of having a biological child: this life saving drug better be worth it;
36. Emergent theme: I am an anxious person. Too much stress causes lung infections;
37. Emergent theme: One of the most unique and devastating things about our illness: It can be very lonely because we can't come in contact with each other;
38. Emergent theme: Constantly having to relate to people who don't know what it's like to be in this body is tough;
39. Emergent theme: I found it scary to get too attached to other people with CF, so I had a hard time keeping those connections;
40. Emergent theme: Walking that line between sick and not sick, disabled and not disabled-having an invisible illness makes it difficult to know whether to pull that card or tough it out;
41. Emergent theme: I'm not sick enough to be included with the rest of the CF population but I'm not healthy enough to fit in with the normal people;
42. Emergent theme: People don't understand that you're battling between being in feeling normal and being in feeling sick;
43. Emergent theme: I look fine so professors wouldn't understand when I'd be asking for an extension;
44. Emergent theme: People I don't know very well can think that I'm brushing them off when I'm sick too often and have to cancel;
45. Emergent theme: When people say I look great, and I don't feel great it makes me feel rejected even more;

46. Emergent theme: It's challenging to deal with mentally when you feel so horrible on the inside and people are like you look great;
47. Emergent theme: A lot of us suffer with denial-I'm never the first to be checked out;
48. Emergent theme: It's sometimes more challenging when your symptoms are overt -I don't think there's something to hide but some didn't want to share it with the world & that's okay;
49. Emergent theme: I consider myself lucky that I can be walking down the street if I'm not super sick and don't get judged right away;
50. Emergent theme: We're all good actors: we're pretty good at hiding that we have something that's pretty hard to deal with;
51. Emergent theme: Everything is going on internally but externally we can look completely okay-we're pretty good at hiding it;
52. Emergent theme: Walking that line between sick and not sick, disabled and not disabled-having an invisible illness makes it difficult to know whether to pull that card or tough it out;
53. Emergent theme: I'm not sick enough to be included with the rest of the CF population but I'm not healthy enough to fit in with the normal people;
54. Emergent theme: People don't understand that you're battling between being in feeling normal and being in feeling sick;
55. Emergent theme: Sometimes that means explaining things about my illness to my small circle because they don't know what it's like to be us;
56. Emergent theme: It's a different world -our problems are difficult for people who are healthy to understand;
57. Emergent theme: Persons with CF can be close in ways that "normies" can't understand;
58. Emergent theme: We are all coughing and that brings us together but it's also an isolating experience from the rest of the world;
59. Emergent theme: As a teenager I tried so hard to hide this illness and to reject it and as I've grown up I'm slowly learning to accept it;
60. Emergent theme: I learned to stand up for myself and make other connections throughout the hospital;

61. Emergent theme: I've met really nice people- -all these great nurses made me feel less lonely;
62. Emergent theme: CF has meant that I have meaningful connections and strong bonds with friends and family;
63. Emergent theme: CF made me mature a lot quicker;
64. Emergent theme: CF has given me the perspective to focus on what matters-appreciate the moment;
65. Emergent theme: Some days I feel super great/productive and others down in the dumps/what am I doing;
66. Emergent theme: Before all these new medications came out, I changed my career path to make sure I had time to do that within my lifetime;
67. Emergent theme: It took me a long time to say my job is my health. I have CF;
68. Emergent theme: To talk openly with a therapist, I would need to feel like I could let it out without feeling judged;
69. Emergent theme: To open up not being judgemental is one of the most important ones;
70. Emergent theme: Open mindedness and non-judgement go really close together;
71. Emergent theme: For me to talk openly it's important that the counsellor be open-minded, supportive and judges less than a doctor might;
72. Emergent theme: To talk openly with a therapist, they would need to be sincere, open, make you feel welcome, and I'd feel a friendly connection;
73. Emergent theme: Listening and empathy is important;
74. Emergent theme: Being friendly/therapist disclosure puts a human part in therapy;
75. Emergent theme: Good listening is important as well as validation of feelings;
76. Emergent theme: Understand chronic illness and its effect on anxiety and depression;
77. Emergent theme: Important to have skills in chronic illness and all the complexities that come with it-grief, depression, anxiety;
78. Emergent theme: Have good background knowledge of chronic illness;
79. Emergent theme: A psychologist that specializes in chronic illness helped me to accept what was happening to my body;
80. Emergent theme: It's important to understand the CF patient's day to day life, the struggles we go through, for example, loss and that our health declines;

81. Emergent theme: Help parents to cope;
82. Emergent theme: It can help to give a mental health diagnosis and to help people to be honest with themselves;
83. Emergent theme: Empathy is key. Not forcing positivity but meeting clients where they are at no matter how uncomfortable, no matter how dark;
84. Emergent theme: Help us to communicate, put feelings together, understand what's going on and have a plan to cope/progress;
85. Emergent theme: Help us to put emotions into words when we don't understand what we're feeling to find a clear path on what's going on;
86. Emergent theme: Ask the right questions to help us to put things into words and be honest with ourselves;
87. Emergent theme: Connect with us and ask the right questions so that we can gain a deeper awareness and understanding about ourselves;
88. Emergent theme: Use an individualized approach (to meet your patient's personality type and what coping mechanisms work for them);
89. Emergent theme: Use an individualized approach (get to know how we like to be nudged and supported);
90. Emergent theme: Create a safe space for me to learn how to sit with my hard emotions;
91. Emergent theme: Having our nurse remind us that the social work/counselling resource is there;
92. Emergent theme: The CF team should reach out to and refer to social work/mental health more when we've had a hard visit;
93. Emergent theme: Every doctor- when you're dealing with mental health treat the person more as a person then as a medical case;
94. Emergent theme: Therapy helped me to understand my thought process and what was going through my mind;
95. Emergent theme: To get to be honest with yourself you realize some stuff;
96. Emergent theme: It's almost shocking how it can help to understand what we're feeling;
97. Emergent theme: My helpful experiences have always been any therapist who helps me to sit in those dark scary feelings and let me feel what I feel;

98. Emergent theme: Being able to help me learn how to sit with the hard stuff has been a really helpful experience;
99. Emergent theme: Your compassion and empathy create a space for me to let out deep emotions & then know I'm going to be okay;
100. Emergent theme: Being validated is a helpful feeling to have in therapy-feeling heard and seen and understood;
101. Emergent theme: The best therapy sessions are when I feel validated, challenged, probably cried, and I have been given resources to be able to practice;
102. Emergent theme: What makes a session sparkling is when I feel empowered/ I know I've made progress & carried over the skills that I've learned;
103. Emergent theme: Establishing that trust with the therapist allows you to eventually do that with people in your life;
104. Emergent theme: Good listening is important as well as validation of feelings;
105. Emergent theme: When you do not paraphrase well, I feel misunderstood and it's tough to make a connection;
106. Emergent theme: Listen to my needs and where I'm at. Don't push your opinion on me about what I should do or how I should take care of myself;
107. Emergent theme: It's great that they want more input from CF patients because mental health is overlooked and it's part of our health overall;
108. Emergent theme: There's a gap when it comes to our minds and how we wrap our brain around having a chronic illness;
109. Emergent theme: You have to roll with the questions for the good of the study;
110. Emergent theme: Being connected in a group setting gives me more inspiration to talk than filling out a questionnaire-it's more personable;
111. Emergent theme: It would be helpful to get feedback from other CF patients to make them feel like they're not alone and to get a different perspective;
112. Emergent theme: Sharing with others with CF before we finalize the framework they might be inspired, feel validated and less judged;
113. Emergent theme: It's important that this framework gets a stamp of approval/comes from all of us as a community;

114. Emergent theme: Disseminating the framework to counsellors/therapists - medical conferences;
115. Emergent theme: A pamphlet would convey information in a more understandable way and a journal article if you wanted to go more in-depth;
116. Emergent theme: It's important that results are conveyed in our transition visit, that this person exists for you to talk to (social work/counselling)- pamphlets/resource package;
117. Emergent theme: Conferences for professionals, pamphlets for patients across CF Teams & making forums part of the framework of therapy;
118. Emergent theme: This focus group has allowed for us to talk together and connect in our experience;
119. Emergent theme: We have all found some common ground here-it's a really nice way to gain perspective;
120. Emergent theme: It's cool being in a video call where you can see and hear people coughing like you, but you don't have to mute yourself-you can just let it out;
121. Emergent theme: Group empathy and mutual support;
122. Emergent theme: This focus group has allowed for us to talk together and connect in our experience – I feel understood, valued and heard;
123. Emergent theme: This focus group has allowed for us to talk together and connect in our experience – I feel honoured to know all of you;
124. Emergent theme: It would be great to have an online forum to be able to connect as a CF community;
125. Emergent theme: There is an existing forum CF Ties;
126. Emergent theme: It's the first time I have interacted with other people with CF -I think it would be nice to have more of that;
127. Emergent theme: It would be nice to interact more with others with CF-here are the supports and connections.

Focus Group Two

1. Emergent theme: You're the poster child for CF in Ottawa;
2. Emergent theme: I love the fact that I had CF because I was an individual;
3. Emergent theme: I never let CF hold me back-I never saw it as an excuse to not do something;

4. Emergent theme: CF has a lot to do with the way you're raised-my mom said this is not going to define you;
5. Emergent theme: I was upfront about my CF, everybody knew;
6. Emergent theme: I can relate to thinking I'm making other people sick. I'm a burden;
7. Emergent theme: I've been secretive of my CF since diagnosis- It's not something I am;
8. Emergent theme: I felt like a burden for most of my youth, that I was inferior to others because I had CF;
9. Emergent theme: I felt self-conscious and ashamed; I didn't want any of my peers to know I had CF;
10. Emergent theme: I did feel like I was bothering people as a child;
11. Emergent theme: I'm a perfectionist so CF just adds to my feeling of not being good enough;
12. Emergent theme: It took me five years to self-declare to my colleagues that I had CF;
13. Emergent theme: My purpose is to educate the new parents with kids with CF: it's not the end of the world unless you want it to be;
14. Emergent theme: I couldn't imagine what life was like without physio before transplant. I never want to do that stuff again;
15. Emergent theme: I couldn't keep up when I was a kid;
16. Emergent theme: We all have CF to varying degrees. Some of us do physio for five minutes and some for two hours;
17. Emergent theme: I did physio 20 minutes a day but otherwise so much energy to burn;
18. Emergent theme: As a child I was able to do a lot of sports and do things my parents put me in;
19. Emergent theme: CF day to day prior to transplant- two hours of physio each day;
20. Emergent theme: As I got older, and I started to get more sick I didn't want to go outside my bubble;
21. Emergent theme: As I got older my coughing got worse and it would hurt more;
22. Emergent theme: There was a decline in my ability to do sports, but I tried to work around it;
23. Emergent theme: In later life, pre-Trikafta, my health with CF took a turn for the worse;
24. Emergent theme: I decided I am going to quit work to focus on my health;

25. Emergent theme: It takes a lot of work to keep my lung function at a very good level-two-three hours of treatments;
26. Emergent theme: CF is sneaky-I can think I feel super good and then Hemoptysis and hospital;
27. Emergent theme: CF can be sneaky. You think you are doing well and then you are taking two steps backward;
28. Emergent theme: When family realize the severity, they get worried;
29. Emergent theme: I self-censor so as not to worry family;
30. Emergent theme: CF limited me relationship wise-I didn't think I was able to keep up;
31. Emergent theme: There was a lot of working around it so that it seems like you can keep up in relationships;
32. Emergent theme: Relationships didn't work out-I didn't feel like I was ready or mature enough;
33. Emergent theme: With CF it's hard to find a partner because it's a bit of a stigmatic- I know you really like me but I can die someday soon, I can't have kids;
34. Emergent theme: With CF it's hard to find a partner who will stick by you, but I did;
35. Emergent theme: If you can find the right person, they have to understand you may have to move on without me;
36. Emergent theme: My coughing was triggering for my partner who had survived trauma: she thought I'm going to die;
37. Emergent theme: I found out about CF shortly after birth-early diagnosis;
38. Emergent theme: I found out about CF after my son was diagnosed-late diagnosis;
39. Emergent theme: I didn't show any symptoms really until I was diagnosed in my 30s;
40. Emergent theme: I found out about CF through issues with infertility-late diagnosis;
41. Emergent theme: I had milder symptoms than my son who has a more typical CF – doctors did not diagnose me accurately;
42. Emergent theme: I didn't show any symptoms really until I was diagnosed in my 30s;
43. Emergent theme: I found out about CF through issues with infertility-late diagnosis;
44. Emergent theme: It's important to stay in a career that had good health care and life insurance and afforded me flexible hours;

45. Emergent theme: It is difficult to find a job that will cover medical insurance in my small town;
46. Emergent theme: I wanted to be a firefighter but then eh you're a liability;
47. Emergent them: Sometimes the party takes you places you weren't expecting-with CF it's important to find a job with a good health care plan;
48. Emergent theme: It took a big toll on my mental and physical health, vying for that government job;
49. Emergent theme: I wanted the government job for the benefits for myself and my son;
50. Emergent theme: The drug is like a miracle. We wouldn't have had transplants;
51. Emergent theme: This magic pill, Trikafta, would mean that I could focus on things I love rather than on treatments-I'd take it;
52. Emergent theme: I'm grateful but also envious. I'd like to think our struggles helped somehow;
53. Emergent theme: I was on the double lung transplant list-Trikafta has been a huge game changer for me;
54. Emergent theme: Trikafta has changed that for me to a certain extent;
55. Emergent theme: Trikafta has changed this for me – not having to cough every morning;
56. Emergent theme: I really didn't feel like I was worthy because I could do more stuff than the other kids;
57. Emergent theme: I didn't feel like I was worthy of being at CF camp, but then I couldn't keep up with my friends outside;
58. Emergent theme: I begged to go but then wanted to go home because these people were so much sicker than I;
59. Emergent theme: You feel like you belong. I'm not alone;
60. Emergent them: Cepacia was rampant;
61. Emergent theme: Regarding CF camp-a UK funded experiment with innocent Canadian kids. It makes me paranoid and shapes who I am today;
62. Emergent theme: We couldn't talk to each other, and it was like a bad thing to get together;
63. Emergent theme: Isolation from others with CF-it is rare for me to have contact with other CFers;

64. Emergent theme: We can't talk to each other. We can't even talk in the doorways at clinic or anything;
65. Emergent theme: I can relate to thinking I'm making other people sick. I'm a burden;
66. Emergent theme: Mental aspects I'm faced with-I've been secretive about my CF).
67. Emergent theme: I felt like a burden for most of my youth, that I was inferior to others because I had CF;
68. Emergent theme: I felt self-conscious and ashamed;
69. Emergent theme: I did feel like I was bothering people as a child;
70. Emergent theme: I'd make sure that a loud noise came on before I stared coughing. I tried not to bother people;
71. Emergent theme: Sometimes I felt guilty using (government) services that would benefit me;
72. Emergent theme: I'm a perfectionist so CF just adds to my feeling of not being good enough;
73. Emergent theme: Mental issues - there is always a voice in the back of my mind saying you should be producing more but CF makes it worse;
74. Emergent theme: I had survivor's guilt after transplant;
75. Emergent theme: I'd make sure that a loud noise came on before I started coughing. I tried not to bother people;
76. Emergent theme: Disclosing my CF at work was difficult doing it enough times they just get normalized to it;
77. Emergent theme: I hid in the stairwell to do my treatments;
78. Emergent theme: Medications are hard to do around friends -doing that work around them. So I'd come home tired and skip it;
79. Emergent theme: Disclose and risk not getting the job you want/ conceal, and you could push too hard and get worse;
80. Emergent theme: It can be a driving force and a delicate balance because your health can take a toll;
81. Emergent theme: I didn't want any of my peers to know I had CF;
82. Emergent theme: I couldn't keep up when I was a kid-I could pass off that I had asthma or allergies;

83. Emergent theme: I've been secretive of having to take a hospital break;
84. Emergent theme: I've been secretive of my CF since diagnosis- It's not something I am;
85. Emergent theme: I concealed my CF at work and did not let my family know the severity until I got put on the transplant list and had no choice;
86. Emergent theme: It took me five years to self-declare to my colleagues that I had CF;
87. Emergent theme: I was upfront about my CF, everybody knew; Emergent theme: I'm so forward and upfront about my CF;
88. Emergent theme: Mental aspects I'm faced with-I've been secretive about my CF;
89. Emergent theme: Perhaps being more open with it is not necessarily a bad thing?;
90. Emergent theme: Contrary to what I thought maybe important to let others know that people are very understanding;
91. Emergent theme: Disclosing when the work culture was right was a good decision for me;
92. Emergent theme: When I disclosed my CF to management, they at first tried to accommodate me;
93. Emergent theme: Disclosing my CF at work was difficult doing it enough times they just get normalized to it;
94. Emergent theme: Disclosing my CF at work was difficult doing it enough times they just get normalized to it-you help them to kind of be compassionate;
95. Emergent theme: I didn't want any of my peers to know I had CF;
96. Emergent theme: I couldn't keep up when I was a kid-I could pass off that I had asthma or allergies;
97. Emergent theme: I've been secretive of having to take a hospital break;
98. Emergent theme: I've been secretive of my CF since diagnosis- It's not something I am;
99. Emergent theme: I concealed my CF at work and did not let my family know the severity until I got put on the transplant list and had no choice;
100. Emergent theme: It took me five years to self-declare to my colleagues that I had CF;
101. Emergent theme: Know that not all patients are the same;
102. Emergent theme: Be very knowledgeable about CF - not everyone is the same, treatments, conditions, uncertainty;
103. Emergent theme: It's different for everybody but there are also commonalities with CF in terms of the progression;

104. Emergent theme: Come in with a clean slate. Not all CF patients are the same;
105. Emergent theme: Important to have knowledge of CF but also recognize that we are all persons first/we are so many other things -I don't want to only focus on CF;
106. Emergent theme: You're the poster child for CF in Ottawa;
107. Emergent theme: I love the fact that I had CF because I was an individual;
108. Emergent theme: I'm so forward and upfront about my CF;
109. Emergent theme: I wanted to be a firefighter but then eh you're a liability;
110. Emergent theme: I never let CF hold me back-I did everything my mom put me in;
111. Emergent theme: I never let CF hold me back-I never saw it as an excuse to not do something;
112. Emergent theme: I didn't live my life knowing or feeling like I could die tomorrow;
113. Emergent theme: When I was younger, I used CF as empowerment. Out to prove everybody wrong;
114. Emergent theme: Having other health challenges helped me to accept CF. It was just another thing;
115. Emergent theme: CF has a lot to do with the way you're raised-my mom said this is not going to define you;
116. Emergent theme: Our upbringing/environment has a huge influence on who we are today;
117. Emergent theme: My mom never treated me differently. I was just assuming I was like everybody else;
118. Emergent theme: Very supportive parents- my parents put me in lots of activities (sports, clarinet lessons, breathing exercises) that would help clear things out;
119. Emergent theme: CF and meaning and purpose in life-live life full;
120. Emergent theme: Treatments are pretty exhausting but it's the way I can continue to contribute to society;
121. Emergent theme: You want to become a productive member of society;
122. Emergent theme: I want to contribute to society-give back;
123. Emergent theme: When you're told you wouldn't live past the age of 25, you start doing all the things you want in life;
124. Emergent theme: I never took drugs because just in case I needed a lung transplant I didn't want to botch it up;

125. Emergent theme: When I was younger, I used CF as empowerment. Out to prove everybody wrong;
126. Emergent theme: When I was younger, I experienced life as much as I could;
127. Emergent theme: My purpose is to educate the new parents with kids with CF;
128. Emergent theme: My purpose is to educate the new parents with kids with CF - it's not the end of the world unless you want it to be;
129. Emergent theme: CF taught me not to take anything for granted;
130. Emergent theme: With CF I had to become very organized which has helped me as a person and professionally;
131. Emergent theme: Learning to Prioritize what really matters vs having no time for BS;
132. Emergent theme: I'm here if you need me -don't be too nosy;
133. Emergent theme: I want to have full trust in you that I can tell you anything-almost like a lawyer but more compassionate;
134. Emergent theme: Be empathetic, teach me different techniques, help me to grow from each therapeutic experience;
135. Emergent theme: I want to have full trust in you that I can tell you anything-non-judgement;
136. Emergent theme: Sparkling moments in a session include humour and learning from the session;
137. Emergent theme: It is helpful for a counsellor to be down to earth, forthcoming, easy to talk to;
138. Emergent theme: Know that not all CF patients are the same;
139. Emergent theme: Be very knowledgeable about CF -not everyone is the same, treatments, conditions, uncertainty;
140. Emergent theme: Important to have knowledge of CF but also recognize that we are all persons first/we are so many other things -I don't want to only focus on CF;
141. Emergent theme: Not just textbook knowledge but real experience with CFers;
142. Emergent theme: The more experience that the counselor has with CF patients the better;
143. Emergent theme: Having knowledge and experience with CF-what we can go through, for example, post-transplant;
144. Emergent theme: Be aware of medications, interactions, and the long-term effects;

145. Emergent theme: Tell CF patients what the progression is going to be so they can keep an eye out for things and overall help us prepare for the future;
146. Emergent theme: Be aware of services and reassure me that it is okay using them;
147. Emergent theme: Knowing good medication routines, stressors, the progression, and financials that come with CF;
148. Emergent theme: The benefits of having a non-CF counsellor is they are not focused mainly on your CF, transplant or whatever;
149. Emergent theme: Mindfulness exercises at the beginning of sessions really make a difference;
150. Emergent theme: Helpful in therapy-meditation, pointing out patterns and books to read;
151. Emergent theme: Having a meditation to ground is a good start;
152. Emergent theme: Be empathetic, teach me different techniques, help me to grow from each therapeutic experience;
153. Emergent theme: Sparkling moments in a session include humour and learning from the session;
154. Emergent theme: When I fall back a few steps remind me of some things we've worked on in the past;
155. Emergent theme: Mindfulness exercises at the beginning of sessions really make a difference;
156. Emergent theme: Not just old-fashioned talk therapy but look at creative options that resonate with me to deal with things;
157. Emergent theme: It's different for everybody but there are also commonalities with CF in terms of the progression;
158. Emergent theme: Tell CF patients what the progression is going to be so they can keep an eye out for things and overall help us prepare for the future;
159. Emergent theme: Come in with a clean slate. Not all CF patients are the same;
160. Emergent theme: Have a background knowledge of what CF is and that CF people are the most positive people you'll ever meet;
161. Emergent theme: Mindfulness exercises/checking in with ourselves/clearing our minds, what a difference that makes;

162. Emergent theme: When a therapist has scientific explanations for why you are feeling stress it can give you a lot of reassurance;
163. Emergent theme: I self-censor so as not to worry family; Emergent theme: Having one person that will listen and you can tell the truth to is amazing;
164. Emergent theme: It's advantageous to be in a group with others with CF-sharing of ideas/brainstorming;
165. Emergent theme: Feedback on PAR: People who have CF are better to give feedback on the framework than doctors;
166. Emergent theme: Feedback re sharing the framework with other CF patients at the Ottawa clinic: Yes, share;
167. Emergent theme: Ideas re dissemination of results: No pamphlets;
168. Emergent theme: Ideas re dissemination of results: get the information out in as many ways as possible;
169. Emergent theme: Ideas re dissemination of results: I think dissemination to counsellor/therapist vs patient should not be the same;
170. Emergent theme: Ideas re dissemination of results: for patients it could be a short video;
171. Emergent theme: Ideas re dissemination of results: if you want more information or for counsellors/therapists a published paper;
172. Emergent theme: Ideas re dissemination of results: create a national registry for CF groups/information sessions;
173. Emergent theme: Ideas re dissemination of results: a medical study journaled might produce more kickback in other clinics;
174. Emergent theme: Ideas re dissemination of results: have the information available on CF Canada website;
175. Emergent theme: It's advantageous to be in a group with others with CF-sharing of ideas/brainstorming;
176. Emergent theme: I love everybody in this group and feel like I can reach out to you.

Focus Group Three

1. Emergent theme: Sometimes I feel I'm too healthy to be in the sick life, and too sick to be in the healthy life;

2. Emergent theme: Understand that our normal isn't the quote normal day to day;
3. Emergent theme: Time management is a problem - it's crazy how time consuming our life is compared to normal folk;
4. Emergent theme: That constant struggle of having to stay on top of things day to day;
5. Emergent theme: It's very time-consuming day to day-it really makes you appreciate the time that you do have;
6. Emergent theme: The two main problems with CF personally are motivation for treatments: that ties into mental health;
7. Emergent theme: Motivation for treatment is a problem;
8. Emergent theme: I struggle with having to do my treatments 100% right - I've been trying to accept it's okay to just do your best;
9. Emergent theme: I haven't been really good at taking care of my CF-I'm full of shit;
10. Emergent theme: A lot of people don't understand just how all-encompassing CF can be;
11. Emergent theme: People have preconceived notions of what CF is;
12. Emergent theme: CF is going to come up on a social level. Being open and upfront and educating people is part of the day to day;
13. Emergent theme: I'm fine as a default - I have to be strong for the people around me or else you're going to freak out;
14. Emergent theme: I got messages that I didn't want to bother and I didn't feel comfortable telling them I crashed;
15. Emergent theme: It's opened conversations with friends, but I've also felt shame about being exhausted and having to cancel;
16. Emergent theme: CF has allowed for vulnerable conversations with friends: our pain may be different, but we can find community;
17. Emergent theme: I'm not going to say I broke up my parent's relationship but I'm sure that it was definitely difficult;
18. Emergent theme: My family is unable to help and guide me because they're dealing with their own issues on how to deal with me being sick;
19. Emergent theme: I block my family out as to what's happening with my body because they tend to make my CF about them;

20. Emergent theme: Mental health in CF really do go together and I feel like there's a lot of people who bury that-in part to be strong for your family;
21. Emergent theme: I've been apprehensive about dating. Would it be like what does the future look like if you have such a short life expectancy;
22. Emergent theme: I used to feel shame from being apprehensive about dating;
23. Emergent theme: Intimacy is a problem: I can do a load of laundry and then I'm mentally and physically done;
24. Emergent theme: Marriage-do you wanna prepare your partner to bury you?;
25. Emergent theme: Having to have a different conversation about having kids-the whole shooting blanks kind of thing;
26. Emergent theme: Fertility, it' a big deal for CF: you have this image in your mind of what you want to achieve and then there's this on a platter. Deal with it;
27. Emergent theme: I am my fiercest advocate. When you get into that kind of mentality it's hard to let people in;
28. Emergent theme: Now I have a supportive partner but not in the past -why would I pursue a future with you when you have such a low life expectancy?;
29. Emergent theme: There's a spectrum of how CF manifests for different people;
30. Emergent theme: They'd have to have knowledge that CF is a spectrum-it affects everybody differently and sometimes where you are on the spectrum changes day to day;
31. Emergent theme: There's a spectrum of how CF manifests for different people-my lungs are good but I have digestive problems;
32. Emergent theme: CF as spectrum it doesn't affect everyone the same way -if I don't have my enzymes forget eating;
33. Emergent theme: As I age life day to day with CF has gotten easier but harder-my body is like a car after that warranty;
34. Emergent theme: Now it's about managing expectations because my lungs have plummeted;
35. Emergent theme: The day-to-day stuff-it's like an evolving situation;
36. Emergent theme: The struggle to balance how much we can and cannot do-our health fluctuates. I've taken a dive these last few years;

37. Emergent theme: My PFTs went down to a certain level and stayed there-If you don't do anything it doesn't work. It's something I struggle;
38. Emergent theme: Today is really crappy and I'd much rather be suntanning but I'm puking in my PJs all day and I'm going to count that as a win;
39. Emergent theme: When I'm super sick I go into this dark hole, where I'm done -I need a counselor who's gonna be like sorry you're living, and you better buckle up;
40. Emergent theme: Witty, dark humour we're all very dark;
41. Emergent theme: We are a dark disease and sometimes there's going to be times where we're going to be in a dark place - it's not a personal attack;
42. Emergent theme: Be an ally - have a thick skin. You get a bit of dark humour when you have our condition;
43. Emergent theme: We're sick. That's what we do. Welcome to the dark side-join the club;
44. Emergent theme: If I'm coughing, I promise I will not give you COVID. This is my day-to-day life;
45. Emergent theme: With COVID I feel the need to justify to people like I cough I won't get you sick;
46. Emergent theme: I think we're going to feel the repercussions of COVID for a while-people are going to be hypersensitive about people coughing around them;
47. Emergent theme: People might assume that you have COVID when you don't;
48. Emergent theme: You definitely see people's true colours in this COVID time-they are ignorant to the impact COVID might have;
49. Emergent theme: You have both sides-people being thoughtful to the potential impact of COVID on us and then the other end of the spectrum;
50. Emergent theme: The whole COVID thing I got nothing-no concern;
51. Emergent theme: A supportive boss who understands the risks for CF during COVID).
52. Emergent theme: People not getting the serious impact of COVID on CF -are you worried that we'll infect you;
53. Emergent theme: People not getting the serious impact of COVID on CF -I'm struggling;
54. Emergent theme: Now in COVID I can't just wake up and get out of bed and run outside-I have to hit all these steps first;

55. Emergent theme: Especially during COVID we have to balance the scales before we leave-is this worth it?;
56. Emergent theme: COVID exacerbated the whole mental part after my breakup-but right now everything's pretty good;
57. Emergent theme: The two main problems with CF personally are motivation for treatments - that ties into mental health;
58. Emergent theme: It's been hard to find the motivation for treatments these last few months during COVID;
59. Emergent theme: COVID has helped regarding treatments: we're sitting at home and have the time;
60. Emergent theme: One of the positive impacts of living with CF was the ability to adapt, for example during COVID;
61. Emergent theme: Am I going to exhaust myself-that does put a mental load on us. We have a unique mental burden;
62. Emergent theme: Problems living with CF - motivation for treatments, just dealing with people and the mental load;
63. Emergent theme: Managing expectations is a constant struggle: a motivational hazard;
64. Emergent theme: It's all mental. It can be an angel or a devil. I don't have that immediate negative thing when it comes to not adhering to treatments;
65. Emergent theme: Part of the mental load is the survivor looks;
66. Emergent theme: I'm gonna be super happy and up here because I blew a 58 and sometimes, I'll be down here cause I haven't pooped in three days and I'm starving;
67. Emergent theme: Anyone that's not me is the enemy-it's fear driven - I'm always nervous that I don't know if I'll leave through the front doors or the morgue;
68. Emergent theme: CF makes me feel like less than a person: I'm afraid that if I start life CF will come up from behind me and be like nope;
69. Emergent theme: I feel like I'm in a box and I don't know where I fit in life - my depression will always be there, my CF will always be there;
70. Emergent theme: I call it the survivor mode: you just gotta keep moving;
71. Emergent theme: CF definitely has its challenges but overall you just keep going;

72. Emergent theme: The therapist would need to have a keen understanding that carrying a lot of this can be very numbing emotionally;
73. Emergent theme: I'm fine as a default: I need someone to pierce through that;
74. Emergent theme: Especially in hospital we're convincing ourselves we're fine: I don't have time to deal with my emotional mind right now;
75. Emergent theme: Mental health in CF really do go together and I feel like there's a lot of people who bury that;
76. Emergent theme: It's one of the reasons I wanted to do this - I've never met anybody that has CF;
77. Emergent theme: I have not met one person since I've been in Ottawa with CF other than a couple people during the walks with CF - it was great seeing people;
78. Emergent theme: It's great to touch base with other people because we don't have a chance to do this - it was my first time;
79. Emergent theme: I'm very new to interacting with others with CF as well;
80. Emergent theme: Talk about invisible illness, in high school we were searching for the other CF patient, but you can't tell with someone with CF;
81. Emergent theme: She didn't really understand what I had. It's like Dr. Seuss-just because you can't see it doesn't mean it's not there;
82. Emergent theme: CF as a non-visible disability - with the GI issue I've had people ask me if I'm pregnant;
83. Emergent theme: We have worked so hard to end the stigma - the ignorance of people impacts my CF a lot;
84. Emergent theme: You're taught in kindergarten just because you can't see it doesn't mean it's not there;
85. Emergent theme: People know the word CF (publicity), but they don't actually know what it is;
86. Emergent theme: People know the word CF, but they don't actually know what it is. Then you start conversations;
87. Emergent theme: The invisible illness type deal-what do you mean you were sick;
88. Emergent theme: If someone has a visible disability, you're not going to expect them to go up on a ladder - with a non-visible disability it's not that obvious;

89. Emergent theme: I still do feel like kind of a sense of shame disclosing I have CF;
90. Emergent theme: If you look half normal people assume you're normal but inevitably you have to have conversations that are frustrating but necessary;
91. Emergent theme: You kind of want to be passive aggressive when people make snarky comments and raise the same issues;
92. Emergent theme: It's a weird one dealing with something that people can't see and maybe don't understand fully;
93. Emergent theme: CF definitely has its challenges but overall you just keep going;
94. Emergent theme: When I was younger it was the judgement that was the hardest part: if somebody doesn't realize you have a disability;
95. Emergent theme: You don't present like my textbook: I do have CF. I'm not lying;
96. Emergent theme: I sometimes feel the need to define my CF for myself and others;
97. Emergent theme: Sometimes I hate the fact that I need to define CF for others, but I don't have the confidence that I'll be taken care of otherwise;
98. Emergent theme: Sometimes having to define my CF for others brings a little bit of aggression- I need to be in control;
99. Emergent theme: I was in the neuro ward, and they didn't believe me that I had CF;
100. Emergent theme: Having to prove how sick I am-not being believed;
101. Emergent theme: Having a non-visible disability - having to prove how sick I am, but then also there's ways to manage it;
102. Emergent theme: There's no real middle ground: It's very difficult to find that balance of I can do a lot of things I'll tell you if it's too much;
103. Emergent theme: Having a non-visible disability: people are like this is what you need. Instead, we need to walk this together;
104. Emergent theme: With CF being non-visible it's hard for people to see that it's possible to have middle ground;
105. Emergent theme: I try not to use CF as a crutch: I'll let you know if I don't feel good;
106. Emergent theme: With this whole CF I'm an open book: don't assume ask me;
107. Emergent theme: If in a wheelchair, people make assumptions and it's really hard to get away from that;

108. Emergent theme: Something I treasure about having a non-visible disability: we can fly under the radar/choose whether we want people to know;
109. Emergent theme: It's a privilege that sometimes people can't see, to be able to decide;
110. Emergent theme: If it's a visible disability you don't have a choice of whether you can hide that but I do: in certain contexts (dating) I don't want to present it right away;
111. Emergent theme: Just being open with it over the years has helped-although some details that were disclosed in grade school were mortifying;
112. Emergent theme: My CF is non-visible but also visible sometimes;
113. Emergent theme: They just think I have a strange body but it's beautifully strange I assume;
114. Emergent theme: A downside - when filling out forms I don't fall under these categories, yet I'm disabled;
115. Emergent theme: I sometimes feel the need to define my CF for myself and others;
116. Emergent theme: People get uncomfortable whenever I talk about cystic fibrosis: Oh, death. But you might die before me;
117. Emergent theme: Once I felt more comfortable with the concept of death and how I want to live my life I felt a lot more at peace;
118. Emergent theme: I have CF but I'm the sick non sick kid;
119. Emergent theme: CF is not a badge of honour for me. It's just something that I have;
120. Emergent theme: It's the whole mental part - I need to learn to live like I have CF but not let it stop me doing stuff;
121. Emergent theme: Being defined by CF can be depressing;
122. Emergent theme: I didn't have the empathy for people because I was sick, but I wasn't living like I was sick - I had the mentality like people should do the same;
123. Emergent theme: Day to day you feel so normal but, in the hospital, you're not - It's kind of an acceptance thing;
124. Emergent theme: I just felt so different from ever before. I think a lot of it is mental for me;
125. Emergent theme: I struggle a lot with the acceptance side of it that impacts the physical side of it too for me;
126. Emergent theme: CF doesn't define me but it's something I've had to confront more deeply these last few years because of my declining health;

127. Emergent theme: I'm too healthy to be in the sick world then I'm too sick to be in the healthy world;
128. Emergent theme: As much as I don't want CF to be my identity it is - I'm the sick one, I'm the charity case;
129. Emergent theme: My family thinks I use CF as a crutch - hell yeah I do!;
130. Emergent theme: When I was younger, I got used to being a healthy sick kid;
131. Emergent theme: I'm not disabled, I'm in the in between and that's hard to fit in a system that's not designed for it;
132. Emergent theme: It's very time-consuming day to day-it really makes you appreciate the time that you do have;
133. Emergent theme: The way that I cope is by spending time on things that are worth it, that make me happy;
134. Emergent theme: Balancing what you're able to do or not – planning your life and career goals is a constant existential thing to assess;
135. Emergent theme: It's new uncharted territory for the CF community-to live this long, to have a career, relationships or retire;
136. Emergent theme: CF has made me appreciative, want to use my time in a way that's positive for me;
137. Emergent theme: In terms of like my sense of purpose or meaning in life I am more comfortable with the concept of death and having my life priorities;
138. Emergent theme: The other day to day with CF -wanting to make the most of my time while I'm healthy;
139. Emergent theme: It's good to have big dreams but you also have to adjust expectations-I've learned a lot about planning backwards;
140. Emergent theme: In terms of a sense of meaning and purpose what released me from my pain was wanting to be present for my nephew;
141. Emergent theme: Having CF has equipped me with just a very developed sense of compassion and empathy;
142. Emergent theme: No regrets - whatever I do I think is this going to bring me the joy I'm looking for;
143. Emergent theme: If I'm going to give a positive to CF – empathy;

144. Emergent theme: In terms of what's your motivation in life I don't know if CF has changed that for me apart from putting obstacles in my way;
145. Emergent theme: If there's a positive aspect to CF it's let's keep perspective regarding what I can realistically do;
146. Emergent theme: The biggest problem is I gotta live like I have CF which is the whole mental part-the whole getting ready to live longer than you expected;
147. Emergent theme: I live like I don't have CF and the whole notion of what I want shifts depending on the situation - I do want to be happy and make people happy;
148. Emergent theme: One of the positive aspects of CF - every bit of what I do I've earned;
149. Emergent theme: In terms of CF and meaning and purpose in life it really puts a different colour glass through which you see your life;
150. Emergent theme: Fertility, it' a big deal for CF - you have this image in your mind of what you want to achieve and then there's this on a platter. Deal with that;
151. Emergent theme: Trying to manage what I'm supposed to do as a woman even though I don't feel up to it;
152. Emergent theme: You're pointless - are you a real man or woman if you can't procreate;
153. Emergent theme: I had so much rage but in society as a woman you're supposed to be rainbows;
154. Emergent theme: What I need from a social worker/counsellor is empathy/to be on your side -to be a counterpoint to clinic where they're being gruff with you;
155. Emergent theme: I need a counsellor that has thick skin, empathy and can look at me not just as a disease but as a real human being;
156. Emergent theme: I need a counsellor that has thick skin, empathy and can look at me not just as a disease but as a real human being;
157. Emergent theme: We are a dark disease and sometimes there's going to be times where we're going to be in a dark place - it's not a personal attack. Just recognizing that it is what it is;
158. Emergent theme: Be an ally - have a thick skin. You get a bit of dark humour when you have our condition;
159. Emergent theme: I need someone who can adapt to what I need - supportive or being talked straight into the face-you're being too dark. Is that adaptive?;

160. Emergent theme: Be an ally - establish trust by asking me what I need to feel supported;
161. Emergent theme: That ally component is key - I don't need somebody to treat me like a queen. I need somebody treating me like a human being;
162. Emergent theme: I don't want to be abandoned. We need a counsellor who is comfortable to stand beside us when CF gets tough;
163. Emergent theme: I need the therapist to not overstep and to know that they won't leave when CF gets tough;
164. Emergent theme: I need someone to remind me that I am important - CF doesn't define who I am;
165. Emergent theme: I need a counsellor that has thick skin, empathy and can look at me not just as a disease but as a real human being;
166. Emergent theme: I don't need someone to treat me like a CF patient but as a human being;
167. Emergent theme: That ally component is key - I don't need somebody to treat me like a queen. I need somebody treating me like a human being;
168. Emergent theme: It's a bit of a fine line - CF is an overarching theme but there is more to me than CF;
169. Emergent theme: It's a bit of a fine line - understand that physical health is important but there's an overarching theme of wanting to feel normal;
170. Emergent theme: I appreciate when a counsellor is transparent/cooperative - they are there to work together to figure out a plan. It shows that they're willing to listen and adapt to your needs;
171. Emergent theme: Bringing in your own life experiences when I'm feeling insecure makes the session more personal for me;
172. Emergent theme: Trying to understand but acknowledging that you're not an expert in my experience of chronic illness is helpful;
173. Emergent theme: It's important to be able to see you within a reasonable time;
174. Emergent theme: Ensure that if somebody requests support that they actually do get it as opposed to falling through the cracks;
175. Emergent theme: They'd have to have knowledge that CF is a spectrum-it affects everybody differently and sometimes where you are on the spectrum changes day to day;

176. Emergent theme: Understand that our normal isn't the quote normal day to day;
177. Emergent theme: To talk openly I need a counsellor to have empathy, tough skin, to know more about CF not what Wikipedia tells them;
178. Emergent theme: I want somebody who's passionate about CF - or specialized in underlining health issues like invisible illnesses;
179. Emergent theme: It's the greatest thing to have someone that's there for your mental health and then understands what CF is;
180. Emergent theme: It's important to have knowledge of health issues, both the physical and systemic aspect -being able to guide you and connect you to resources where there are legal and financial implications;
181. Emergent theme: In training new therapists or counsellors have them come to clinic and shadow and see it frontline, especially on Fridays;
182. Emergent theme: Being aware of the burden complex - I don't want to burden other people, but I also need to ask for help;
183. Emergent theme: It's important for a counsellor who deals with the CF population to not take it at our word that we're fine because we're used to putting up a front to be strong for others;
184. Emergent theme: It's important for a counsellor who deals with the CF population to not assume that because we're healthy physically, we're healthy emotionally;
185. Emergent theme: Knowing that CFers might not know everything about their illness but are willing to learn;
186. Emergent theme: We're the experts on CF - it's finding a therapist who's willing to turn over the reins;
187. Emergent theme: I'm fine as a default - I need someone to pierce through that;
188. Emergent theme: Help me get to the root of it-let's try to fix the overall issue;
189. Emergent theme: I go to a therapist to guide me, to be present with me when I'm sick and to talk about the uncomfortable side of CF;
190. Emergent theme: Especially if I'm in hospital I would need a therapist to talk to me not at me - I want to have a conversation;
191. Emergent theme: I need a counselor who's gonna take the gross the uncomfortable and work with me even if I push him or her away;

192. Emergent theme: It's helpful to have a counsellor where you're forced to face those harder points that you were afraid of or weren't aware of;
193. Emergent theme: I prefer a structured approach - that the counsellor would help push you forward as opposed to just being listening and empathetic;
194. Emergent theme: Keep it very grounded - I don't need a hero complex; I need that's a lot to carry what do you need to self-care;
195. Emergent theme: I need boundaries to be an ongoing conversation - when to push and not push knowing that eventually the lines will need to move to delve into the touchy areas, the dark stuff;
196. Emergent theme: I need a counselor who's willing to walk with me, not me yelling after them to catch up;
197. Emergent theme: Have a personalized approach and be cognisant that we're knowledgeable as a patient group about what is affecting us;
198. Emergent theme: Instead of asking me predetermined questions with predetermined answers have a conversation with me about what matters to me;
199. Emergent theme: Being able to read the body language is a very big thing for me - how you react will determine how I respond;
200. Emergent theme: I need the counsellor to adjust what we're doing to what's feasible for me right now;
201. Emergent theme: The therapist would have to have that balance between allowing us to feel those feelings and then okay let's move on;
202. Emergent theme: It's helpful when a therapist understands when interconnected factors connect and when to focus on one thing;
203. Emergent theme: My ideal session - this is how my brain works, this is what I need and the counsellor remembering the micro details;
204. Emergent theme: It's helpful when a therapist is gentle and respectful with transitions - I don't want to interrupt your flow, but the session is ending;
205. Emergent theme: I need a strategy to practice something - I need that as something to hold onto;
206. Emergent theme: You have to tell me shut up- OK times up;

207. Emergent theme: Let's end the session on a positive note, and focus on what we can work on next session;
208. Emergent theme: Engage in a dialogue with me - pushing on certain issues, letting others go-I don't want to spin around in my own problems. I want to leave with a bit more clarity;
209. Emergent theme: With CF there are different mutations - I wish I would've been prepped more;
210. Emergent theme: Sometimes I have struggled emotionally, and I felt that because I wasn't sick enough, I didn't get the support I needed;
211. Emergent theme: During COVID times we don't get to talk in clinic - I think if clinic just offered group opportunities to talk;
212. Emergent theme: What about group therapy sessions with social work facilitating;
213. Emergent theme: My dream sequence - full time mental health services in clinic and the option of group therapy or one to one sessions;
214. Emergent theme: Advocating for yourself is really important- I think that your healthcare should be a joint decision;
215. Emergent theme: The healthcare system/the systemic side of things isn't made to deal with chronic illness that can also be acute sometimes having to advocate and fight for access;
216. Emergent theme: The systemic side of things isn't made to deal with chronic illness that can also be acute sometimes having to explain that;
217. Emergent theme: My most positive experience with a counsellor was with someone who had more of a conversational approach, somebody being authentic;
218. Emergent theme: Engage in a dialogue with me - pushing on certain issues, letting others go-more nuanced;
219. Emergent theme: I have had a few unhelpful experiences and I think the catharsis of this might help;
220. Emergent theme: I had a drug pusher of psychiatrist, and it went from bad to worse - it wasn't about let's get to the root of it;
221. Emergent theme: Unhelpful experiences outside the hospital - sometimes it just feels like therapists just want to get paid;
222. Emergent theme: Unhelpful experiences outside the hospital - a lot of these counselors are very Wikipedia CF;

223. Emergent theme: If I immediately feel like you don't believe me then I no longer feel comfortable;
224. Emergent theme: You should be happy you're alive? Just because I've gotten to this point doesn't mean it's sunshine and rainbows;
225. Emergent theme: Unhelpful experiences outside the hospital - astronomical wait times;
226. Emergent theme: Unhelpful experiences outside the hospital - sometimes it just feels like therapists just want to get paid;
227. Emergent theme: I had a covered appointment that was awash because we mostly did the administrative components and only talked for the last 10 minutes - I left as a result;
228. Emergent theme: It is a spectrum of some days are really good and some days are really bad - it's important for someone to recognize I don't want to talk that day;
229. Emergent theme: Being involved has been valuable - it's appalling that there would ever be a framework just based on the science and not on individual people's experiences;
230. Emergent theme: You guys definitely need us - We're a different kind of sick-in the end I know my body and we know what we need even if you don't;
231. Emergent theme: It makes sense to be included - how can you get a good view of what's going on unless people who are experiencing it tell you;
232. Emergent theme: Our disease is a spectrum and bringing us into it makes sense;
233. Emergent theme: Having this high and mighty well, we're going to study this from afar doesn't really make sense;
234. Emergent theme: It makes sense to include focus groups - We're a different kind of sick-in the end I know my body and we know what we need even if you don't;
235. Emergent theme: The fact that you had us involved from the beginning I actually believe you that you care about our answers and care about our opinion;
236. Emergent theme: People don't necessarily voluntarily tell people what they need, especially when it comes to counselling and mental health. It's good to have the practitioners encourage that out of us;
237. Emergent theme: In terms of this framework, it is crucial to bring in the nurse practitioners because they are fielding it for us;
238. Emergent theme: We should get clinic involved, let them learn from us so future patients can avoid our hiccups;

239. Emergent theme: I had a good experience being a co-facilitator, but I could have benefitted from more decisiveness regarding the expectation of the role;
240. Emergent theme: I really appreciated being involved in the framework, it was great facilitating and I got to share my thoughts too;
241. Emergent theme: Presenting the framework to the CF community would be a good way of communicating with each other;
242. Emergent theme: When disseminating the framework to patients there should be an infographic, a visual component then documentation attached;
243. Emergent theme: Disseminating the framework should be credible, substantive and really showcase the ground we covered;
244. Emergent theme: It's one of the reasons I wanted to do this - I've never met anybody that has CF;
245. Emergent theme: I have not met one person since I've been in Ottawa with CF other than a couple people during the walks with CF - it was great seeing people;
246. Emergent theme: It's great to touch base with other people because we don't have a chance to do this - it was my first time;
247. Emergent theme: There may be lots of coughing but that's part of the gig;
248. Emergent theme: Coughing on purpose during COVID to maintain bubbles - personal space - collective laughter;
249. Emergent theme: I do recognize a lot of what I'm going through in a lot of other people's explanations of things;
250. Emergent theme: It's really valuable being able to connect with each other;
251. Emergent theme: I really resonate with a lot of your great points;
252. Emergent theme: This is amazing how you can relate to everyone's experience;
253. Emergent theme: A lot of things you guys said have resonated with me as well;
254. Emergent theme: I have had a few unhelpful experiences and I think the catharsis of this might help;
255. Emergent theme: It's kinda like a therapy session - I feel like we're all going to wake up and exhale.

Section Two: Focus Group Horizontal Analysis

1. Emergent theme: Just living day to day with CF(RD) is exhausting;

2. Emergent theme: I've been struggling with treatment burden for a really long time;
3. Emergent theme: With CF(RD) there is a lot of fatigue, so I am a very big homebody;
4. Emergent theme: It's exhausting working a job where you're constantly on your feet every day;
5. Emergent Theme: I have CF related diabetes (CFRD) which requires blood sugar checking and insulin injection in addition to my lung therapies;
6. Emergent theme: You're born with this so you should know how to deal with it but it always throws you a curveball-it's not easy;
7. Emergent theme: I have CF(RD) and multiple diagnoses - I stopped taking care of myself as a whole;
8. Emergent theme: We all have CF to varying degrees. Some of us do physio for five minutes and some for two hours;
9. Emergent theme: As I got older, and I started to get more sick I didn't want to go outside my bubble;
10. Emergent theme: As I got older my coughing got worse and it would hurt more;
11. Emergent theme: CF is sneaky-I can think I feel super good and then Hemoptysis and hospital;
12. Emergent theme: CF can be sneaky. You think you are doing well and then you are taking two steps backward;
13. Emergent theme: Understand that our normal isn't the quote normal day to day;
14. Emergent theme: Sometimes I feel I'm too healthy to be in the sick life, and too sick to be in the healthy life;
15. Emergent theme: Time management is a problem - it's crazy how time consuming our life is compared to normal folk;
16. Emergent theme: That constant struggle of having to stay on top of things day to day;
17. Emergent theme: The two main problems with CF personally are motivation for treatments: that ties into mental health;
18. Emergent theme: Motivation for treatment is a problem;
19. Emergent theme: I struggle with having to do my treatments 100% right - I've been trying to accept it's okay to just do your best;
20. Emergent theme: I haven't been really good at taking care of my CF-I'm full of shit;

21. Emergent theme: My inability to open up comes back to a childhood of loneliness and not having meaningful connections/just having doctors in my life and nurses;
22. Emergent theme: CF is a lonely disease-I've lost friends throughout because it's hard to be present if you're in the hospital or trying to recover;
23. Emergent theme: CF has meant that I have meaningful connections and strong bonds with friends and family;
24. Emergent theme: It's about having a smaller circle of people you really trust and that understand;
25. Emergent theme: When family realize the severity, they get worried;
26. Emergent theme: I self-censor so as not to worry family;
27. Emergent theme: There was a lot of working around it so that it seems like you can keep up in relationships;
28. Emergent theme: Relationships didn't work out-I didn't feel like I was ready or mature enough;
29. Emergent theme: With CF it's hard to find a partner because it's a bit of a stigmatic- I know you really like me but I can die someday soon, I can't have kids;
30. Emergent theme: With CF it's hard to find a partner who will stick by you, but I did;
31. Emergent theme: If you can find the right person, they have to understand you may have to move on without me;
32. Emergent theme: My coughing was triggering for my partner who had survived trauma: she thought I'm going to die;
33. Emergent theme: People have preconceived notions of what CF is;
34. Emergent theme: CF is going to come up on a social level. Being open and upfront and educating people is part of the day to day;
35. Emergent theme: I'm fine as a default - I have to be strong for the people around me or else you're going to freak out;
36. Emergent theme: I got messages that I didn't want to bother and I didn't feel comfortable telling them I crashed;
37. Emergent theme: My family is unable to help and guide me because they're dealing with their own issues on how to deal with me being sick;

38. Emergent theme: I block my family out as to what's happening with my body because they tend to make my CF about them;
39. Emergent theme: CF has allowed for vulnerable conversations with friends: our pain may be different, but we can find community;
40. Emergent theme: Intimacy is a problem: I can do a load of laundry and then I'm mentally and physically done;
41. Emergent theme: Having to have a different conversation about having kids-the whole shooting blanks kind of thing;
42. Emergent theme: Fertility, it' a big deal for CF: you have this image in your mind of what you want to achieve and then there's this on a platter. Deal with it;
43. Emergent theme: Marriage-do you wanna prepare your partner to bury you?;
44. Emergent theme: Now I have a supportive partner but not in the past -why would I pursue a future with you when you have such a low life expectancy?;
45. Emergent theme: Due to COVID trying to find a remote job is difficult, and a job with benefits is a pressing matter and adds another layer;
46. Emergent theme: I worked a full-time job before COVID which I haven't been super bored about;
47. Emergent theme: I was also working before COVID and then I wasn't able to and went back to school -fatigue makes it hard to manage things;
48. Emergent theme: COVID has meant that I am the healthiest I have ever been because I'm not interacting with people;
49. Emergent theme: We're sick. That's what we do. Welcome to the dark side-join the club;
50. Emergent theme: If I'm coughing, I promise I will not give you COVID. This is my day-to-day life;
51. Emergent theme: With COVID I feel the need to justify to people like I cough I won't get you sick;
52. Emergent theme: You definitely see people's true colours in this COVID time-they are ignorant to the impact COVID might have;
53. Emergent theme: People not getting the serious impact of COVID on CF -I'm struggling;
54. Emergent theme: Especially during COVID we have to balance the scales before we leave-is this worth it;

55. Emergent theme: COVID exacerbated the whole mental part after my breakup-but right now everything's pretty good;
56. Emergent theme: The two main problems with CF personally are motivation for treatments - that ties into mental health;
57. Emergent theme: It's been hard to find the motivation for treatments these last few months during COVID;
58. Emergent theme: One of the positive impacts of living with CF was the ability to adapt, for example during COVID;
59. Emergent theme: One of the most unique and devastating things about our illness: It can be very lonely because we can't come in contact with each other;
60. Emergent theme: Constantly having to relate to people who don't know what it's like to be in this body is tough;
61. Emergent theme: I found it scary to get too attached to other people with CF, so I had a hard time keeping those connections;
62. Emergent theme: We couldn't talk to each other, and it was like a bad thing to get together;
63. Emergent theme: We can't talk to each other. We can't even talk in the doorways at clinic or anything;
64. Emergent theme: You're the poster child for CF in Ottawa;
65. Emergent theme: Talk about invisible illness, in high school we were searching for the other CF patient, but you can't tell with someone with CF;
66. Emergent theme: It's one of the reasons I wanted to do this - I've never met anybody that has CF;
67. Emergent theme: I have not met one person since I've been in Ottawa with CF other than a couple people during the walks with CF - it was great seeing people;
68. Emergent theme: It's great to touch base with other people because we don't have a chance to do this - it was my first time;
69. Emergent theme: If one mental health piece is overlooked, then your physical health is going to go down;
70. Emergent theme: It's damned kind of either way - mental health and physical health are connected in CF;

71. Emergent theme: It's this double-edged sword-you need to get out of bed to do your treatments, but your mind is making you feel heavy on top of CF;
72. Emergent theme: Stigma, CF and mental health - people think you've had that your whole life you should be used to it but it's been a burden;
73. Emergent theme: The shame part of CF - it's something that we're born with so we're supposed to be experts but it's crushing;
74. Emergent theme: I'm mad at the government: they're making me choose between my health (a new CF drug) and having a baby;
75. Emergent theme: It was a grieving process to decide to foster children instead of having a biological child: this life saving drug better be worth it;
76. Emergent theme: I am an anxious person. Too much stress causes lung infections;
77. Emergent theme: Am I going to exhaust myself-that does put a mental load on us. We have a unique mental burden;
78. Emergent theme: Problems living with CF - motivation for treatments, just dealing with people and the mental load;
79. Emergent theme: Part of the mental load is the survivor looks;
80. Emergent theme: I'm gonna be super happy and up here because I blew a 58 and sometimes, I'll be down here cause I haven't pooped in three days and I'm starving;
81. Emergent theme: CF makes me feel like less than a person: I'm afraid that if I start life CF will come up from behind me and be like nope;
82. Emergent theme: I call it the survivor mode: you just gotta keep moving;
83. Emergent theme: CF definitely has its challenges but overall you just keep going;
84. Emergent theme: The therapist would need to have a keen understanding that carrying a lot of this can be very numbing emotionally;
85. Emergent theme: I'm fine as a default: I need someone to pierce through that;
86. Emergent theme: Especially in hospital we're convincing ourselves we're fine: I don't have time to deal with my emotional mind right now;
87. Emergent theme: Mental health in CF really do go together and I feel like there's a lot of people who bury that;
88. Emergent theme: You're the poster child for CF in Ottawa;
89. Emergent theme: I had survivor's guilt after transplant;

90. Emergent theme: A lot of us suffer with denial-I'm never the first to be checked out;
91. Emergent theme: Sometimes having to define my CF for others brings a little bit of aggression- I need to be in control;
92. Emergent theme: The shame part of CF - it's something that we're born with so we're supposed to be experts but it's crushing;
93. Emergent theme: I still do feel like kind of a sense of shame disclosing I have CF;
94. Emergent theme: I've been secretive of my CF since diagnosis- It's not something I am;
95. Emergent theme: We have worked so hard to end the stigma - the ignorance of people impacts my CF a lot;
96. Emergent theme: The invisible illness type deal-what do you mean you were sick;
97. Emergent theme: You kind of want to be passive aggressive when people make snarky comments and raise the same issues;
98. Emergent theme: When I was younger it was the judgement that was the hardest part: if somebody doesn't realize you have a disability;
99. Emergent theme: You don't present like my textbook: I do have CF. I'm not lying;
100. Emergent theme: I was in the neuro ward, and they didn't believe me that I had CF;
101. Emergent theme: Walking that line between sick and not sick, disabled and not disabled-having an invisible illness makes it difficult to know whether to pull that card or tough it out;
102. Emergent theme: People don't understand that you're battling between being in feeling normal and being in feeling sick;
103. Emergent theme: I've been secretive of having to take a hospital break;
104. Emergent theme: I've been secretive of my CF since diagnosis- It's not something I am;
105. Emergent theme: Perhaps being more open with it is not necessarily a bad thing?;
106. Emergent theme: Disclosing my CF at work was difficult doing it enough times they just get normalized to it;
107. Emergent theme: Disclosing my CF at work was difficult doing it enough times they just get normalized to it-you help them to kind of be compassionate;
108. Emergent theme: We have worked so hard to end the stigma - the ignorance of people impacts my CF a lot;
109. Emergent theme: Having to prove how sick I am-not being believed;

110. Emergent theme: Having a non-visible disability - having to prove how sick I am, but then also there's ways to manage it;
111. Emergent theme: My CF is non-visible but also visible sometimes;
112. Emergent theme: They just think I have a strange body but it's beautifully strange I assume;
113. Emergent theme: I'm too healthy to be in the sick world then I'm too sick to be in the healthy world;
114. Emergent theme: I'm not disabled, I'm in the in between and that's hard to fit in a system that's not designed for it;
115. Emergent theme: I feel like I'm in a box and I don't know where I fit in life - my depression will always be there, my CF will always be there;
116. Emergent theme: Persons with CF can be close in ways that "normies" can't understand;
117. Emergent theme: It's the whole mental part - I need to learn to live like I have CF but not let it stop me doing stuff;
118. Emergent theme: CF doesn't define me but it's something I've had to confront more deeply these last few years because of my declining health;
119. Emergent theme: CF made me mature a lot quicker;
120. Emergent theme: I learned to stand up for myself and make other connections throughout the hospital;
121. Emergent theme: CF has meant that I have meaningful connections and strong bonds with friends and family;
122. Emergent theme: CF has given me the perspective to focus on what matters-appreciate the moment;
123. Emergent theme: CF taught me not to take anything for granted;
124. Emergent theme: CF and meaning and purpose in life-live life full;
125. Emergent theme: When I was younger, I experienced life as much as I could;
126. Emergent theme: CF taught me not to take anything for granted;
127. Emergent theme: Treatments are pretty exhausting but it's the way I can continue to contribute to society;
128. Emergent theme: You want to become a productive member of society;
129. Emergent theme: I want to contribute to society-give back;
130. Emergent theme: My purpose is to educate the new parents with kids with CF;

131. Emergent theme: My purpose is to educate the new parents with kids with CF - it's not the end of the world unless you want it to be;
132. Emergent theme: If there's a positive aspect to CF it's let's keep perspective regarding what I can realistically do;
133. Emergent theme: The way that I cope is by spending time on things that are worth it, that make me happy;
134. Emergent theme: No regrets - whatever I do I think is this going to bring me the joy I'm looking for;
135. Emergent theme: In terms of a sense of meaning and purpose what released me from my pain was wanting to be present for my nephew;
136. Emergent theme: Balancing what you're able to do or not – planning your life and career goals is a constant existential thing to assess;
137. Emergent theme: It's new uncharted territory for the CF community-to live this long, to have a career, relationships or retire;
138. Emergent theme: The biggest problem is I gotta live like I have CF which is the whole mental part-the whole getting ready to live longer than you expected;
139. Emergent theme: If I'm going to give a positive to CF – empathy;
140. Emergent theme: Having CF has equipped me with just a very developed sense of compassion and empathy;
141. Emergent theme: Fertility, it' a big deal for CF - you have this image in your mind of what you want to achieve and then there's this on a platter. Deal with that;
142. Emergent theme: To talk openly with a therapist, I would need to feel like I could let it out without feeling judged;
143. Emergent theme: To open up not being judgemental is one of the most important ones;
144. Emergent theme: Open mindedness and non-judgement go really close together;
145. Emergent theme: For me to talk openly it's important that the counsellor be open-minded, supportive and judges less than a doctor might;
146. Emergent theme: To talk openly with a therapist, they would need to be sincere, open, make you feel welcome, and I'd feel a friendly connection;
147. Emergent theme: Good listening is important as well as validation of feelings;
148. Emergent theme: I want to have full trust in you that I can tell you anything-non-judgement;

149. Emergent theme: I'm here if you need me -don't be too nosy;
150. Emergent theme: I want to have full trust in you that I can tell you anything-almost like a lawyer but more compassionate;
151. Emergent theme: Be empathetic, teach me different techniques, help me to grow from each therapeutic experience;
152. Emergent theme: Sparkling moments in a session include humour and learning from the session;
153. Emergent theme: It is helpful for a counsellor to be down to earth, forthcoming, easy to talk to;
154. Emergent theme: What I need from a social worker/counsellor is empathy/to be on your side -to be a counterpoint to clinic where they're being gruff with you;
155. Emergent theme: I need a counsellor that has thick skin, empathy and can look at me not just as a disease but as a real human being;
156. Emergent theme: We are a dark disease and sometimes there's going to be times where we're going to be in a dark place - it's not a personal attack. Just recognizing that it is what it is;
157. Emergent theme: Be an ally - have a thick skin. You get a bit of dark humour when you have our condition;
158. Emergent theme: I need someone who can adapt to what I need - supportive or being talked straight into the face-you're being too dark. Is that adaptive?;
159. Emergent theme: Be an ally - establish trust by asking me what I need to feel supported;
160. Emergent theme: That ally component is key - I don't need somebody to treat me like a queen. I need somebody treating me like a human being;
161. Emergent theme: I don't want to be abandoned. We need a counsellor who is comfortable to stand beside us when CF gets tough;
162. Emergent theme: I need the therapist to not overstep and to know that they won't leave when CF gets tough;
163. Emergent theme: I need someone to remind me that I am important - CF doesn't define who I am;
164. Emergent theme: I don't need someone to treat me like a CF patient but as a human being;

165. Emergent theme: I appreciate when a counsellor is transparent/cooperative - they are there to work together to figure out a plan. It shows that they're willing to listen and adapt to your needs;
166. Emergent theme: Bringing in your own life experiences when I'm feeling insecure makes the session more personal for me;
167. Emergent theme: Trying to understand but acknowledging that you're not an expert in my experience of chronic illness is helpful;
168. Emergent theme: It's important to be able to see you within a reasonable time;
169. Emergent theme: Understand chronic illness and its effect on anxiety and depression;
170. Emergent theme: Important to have skills in chronic illness and all the complexities that come with it-grief, depression, anxiety;
171. Emergent theme: Have good background knowledge of chronic illness;
172. Emergent theme: A psychologist that specializes in chronic illness helped me to accept what was happening to my body;
173. Emergent theme: It's important to understand the CF patient's day to day life, the struggles we go through, for example, loss and that our health declines;
174. Emergent theme: Not just textbook knowledge but real experience with CFers;
175. Emergent theme: The more experience that the counselor has with CF patients the better;
176. Emergent theme: Be very knowledgeable about CF -not everyone is the same, treatments, conditions, uncertainty;
177. Emergent theme: Knowing good medication routines, stressors, the progression, and financials that come with CF;
178. Emergent theme: Having knowledge and experience with CF-what we can go through, for example, post-transplant;
179. Emergent theme: Be aware of medications, interactions, and the long-term effects;
180. Emergent theme: Tell CF patients what the progression is going to be so they can keep an eye out for things and overall help us prepare for the future;
181. Emergent theme: Be aware of services and reassure me that it is okay using them;
182. Emergent theme: Important to have knowledge of CF but also recognize that we are all persons first/we are so many other things -I don't want to only focus on CF;

183. Emergent theme: The benefits of having a non-CF counsellor is they are not focused mainly on your CF, transplant or whatever;
184. Emergent theme: They'd have to have knowledge that CF is a spectrum-it affects everybody differently and sometimes where you are on the spectrum changes day to day;
185. Emergent theme: To talk openly I need a counsellor to have empathy, tough skin, to know more about CF not what Wikipedia tells them;
186. Emergent theme: It's the greatest thing to have someone that's there for your mental health and then understands what CF is;
187. Emergent theme: It's important to have knowledge of health issues, both the physical and systemic aspect -being able to guide you and connect you to resources where there are legal and financial implications;
188. Emergent theme: I want somebody who's passionate about CF - or specialized in underlining health issues like invisible illnesses;
189. Emergent theme: Being aware of the burden complex - I don't want to burden other people, but I also need to ask for help;
190. Emergent theme: It's important for a counsellor who deals with the CF population to not take it at our word that we're fine because we're used to putting up a front to be strong for others;
191. Emergent theme: It's important for a counsellor who deals with the CF population to not assume that because we're healthy physically, we're healthy emotionally;
192. Emergent theme: Knowing that CFers might not know everything about their illness but are willing to learn;
193. Emergent theme: We're the experts on CF - it's finding a therapist who's willing to turn over the reins;
194. Emergent theme: Empathy is key. Not forcing positivity but meeting clients where they are at no matter how uncomfortable, no matter how dark;
195. Emergent theme: Help us to communicate, put feelings together, understand what's going on and have a plan to cope/progress;
196. Emergent theme: Help us to put emotions into words when we don't understand what we're feeling to find a clear path on what's going on;

197. Emergent theme: Ask the right questions to help us to put things into words and be honest with ourselves;
198. Emergent theme: Connect with us and ask the right questions so that we can gain a deeper awareness and understanding about ourselves;
199. Emergent theme: Help parents to cope;
200. Emergent theme: It can help to give a mental health diagnosis and to help people to be honest with themselves;
201. Emergent theme: Mindfulness exercises at the beginning of sessions really make a difference;
202. Emergent theme: Helpful in therapy-meditation, pointing out patterns and books to read;
203. Emergent theme: Having a meditation to ground is a good start;
204. Emergent theme: When I fall back a few steps remind me of some things we've worked on in the past;
205. Emergent theme: Not just old-fashioned talk therapy but look at creative options that resonate with me to deal with things;
206. Emergent theme: I'm fine as a default - I need someone to pierce through that;
207. Emergent theme: Help me get to the root of it-let's try to fix the overall issue;
208. Emergent theme: I go to a therapist to guide me, to be present with me when I'm sick and to talk about the uncomfortable side of CF;
209. Emergent theme: Especially if I'm in hospital I would need a therapist to talk to me not at me - I want to have a conversation;
210. Emergent theme: I need a counselor who's gonna take the gross the uncomfortable and work with me even if I push him or her away;
211. Emergent theme: It's helpful to have a counsellor where you're forced to face those harder points that you were afraid of or weren't aware of;
212. Emergent theme: I prefer a structured approach - that the counsellor would help push you forward as opposed to just being listening and empathetic;
213. Emergent theme: Keep it very grounded - I don't need a hero complex;
214. Emergent theme: I need boundaries to be an ongoing conversation - when to push and not push knowing that eventually the lines will need to move to delve into the touchy areas, the dark stuff;

215. Emergent theme: Have a personalized approach and be cognisant that we're knowledgeable as a patient group about what is affecting us;
216. Emergent theme: Instead of asking me predetermined questions with predetermined answers have a conversation with me about what matters to me;
217. Emergent theme: Being able to read the body language is a very big thing for me - how you react will determine how I respond;
218. Emergent theme: My ideal session - this is how my brain works, this is what I need and the counsellor remembering the micro details;
219. Emergent theme: I need a strategy to practice something - I need that as something to hold onto;
220. Emergent theme: I need a counselor who's willing to walk with me, not me yelling after them to catch up;
221. Emergent theme: Having our nurse remind us that the social work/counselling resource is there;
222. Emergent theme: The CF team should reach out to and refer to social work/mental health more when we've had a hard visit;
223. Emergent theme: Every doctor- when you're dealing with mental health treat the person more as a person then as a medical case;
224. Emergent theme: It's different for everybody but there are also commonalities with CF in terms of the progression;
225. Emergent theme: Tell CF patients what the progression is going to be so they can keep an eye out for things and overall help us prepare for the future;
226. Emergent theme: Come in with a clean slate. Not all CF patients are the same;
227. Emergent theme: Have a background knowledge of what CF is and that CF people are the most positive people you'll ever meet;
228. Emergent theme: With CF there are different mutations - I wish I would've been prepped more;
229. Emergent theme: Sometimes I have struggled emotionally, and I felt that because I wasn't sick enough, I didn't get the support I needed;
230. Emergent theme: My dream sequence - full time mental health services in clinic and the option of group therapy or one to one sessions;

231. Emergent theme: Advocating for yourself is really important- I think that your healthcare should be a joint decision;
232. Emergent theme: The healthcare system/the systemic side of things isn't made to deal with chronic illness that can also be acute sometimes having to advocate and fight for access;
233. Emergent theme: The systemic side of things isn't made to deal with chronic illness that can also be acute sometimes having to explain that;
234. Emergent theme: Your compassion and empathy create a space for me to let out deep emotions & then know I'm going to be okay;
235. Emergent theme: Being validated is a helpful feeling to have in therapy-feeling heard and seen and understood;
236. Emergent theme: Therapy helped me to understand my thought process and what was going through my mind;
237. Emergent theme: Being able to help me learn how to sit with the hard stuff has been a really helpful experience;
238. Emergent theme: My helpful experiences have always been any therapist who helps me to sit in those dark scary feelings and let me feel what I feel;
239. Emergent theme: The best therapy sessions are when I feel validated, challenged, probably cried, and I have been given resources to be able to practice;
240. Emergent theme: What makes a session sparkling is when I feel empowered/ I know I've made progress & carried over the skills that I've learned;
241. Emergent theme: Establishing that trust with the therapist allows you to eventually do that with people in your life;
242. Emergent theme: Mindfulness exercises/checking in with ourselves/clearing our minds, what a difference that makes;
243. Emergent theme: When a therapist has scientific explanations for why you are feeling stress it can give you a lot of reassurance;
244. Emergent theme: Having one person that will listen and you can tell the truth to is amazing;
245. Emergent theme: I self-censor so as not to worry family;
246. Emergent theme: Good listening is important as well as validation of feelings;
247. Emergent theme: Listen to my needs and where I'm at. Don't push your opinion on me about what I should do or how I should take care of myself;

248. Emergent theme: I had a drug pusher of psychiatrist, and it went from bad to worse - it wasn't about let's get to the root of it;
249. Emergent theme: If I immediately feel like you don't believe me then I no longer feel comfortable;
250. Emergent theme: It is a spectrum of some days are really good and some days are really bad - it's important for someone to recognize I don't want to talk that day;
251. Emergent theme: You should be happy you're alive? Just because I've gotten to this point doesn't mean it's sunshine and rainbows;
252. Emergent theme: In terms of this framework, it is crucial to bring in the nurse practitioners because they are fielding it for us;
253. Emergent theme: Being connected in a group setting gives me more inspiration to talk than filling out a questionnaire-it's more personable;
254. Emergent theme: It's great that they want more input from CF patients because mental health is overlooked and it's part of our health overall;
255. Emergent theme: There's a gap when it comes to our minds and how we wrap our brain around having a chronic illness;
256. Emergent theme: You have to roll with the questions for the good of the study;
257. Emergent theme: It would be helpful to get feedback from other CF patients to make them feel like they're not alone and to get a different perspective;
258. Emergent theme: Sharing with others with CF before we finalize the framework they might be inspired, feel validated and less judged;
259. Emergent theme: It's important that this framework gets a stamp of approval/comes from all of us as a community;
260. Emergent theme: Disseminating the framework to counsellors/therapists - medical conferences;
261. Emergent theme: A pamphlet would convey information in a more understandable way and a journal article if you wanted to go more in-depth;
262. Emergent theme: It's important that results are conveyed in our transition visit, that this person exists for you to talk to (social work/counselling)- pamphlets/resource package;
263. Emergent theme: Conferences for professionals, pamphlets for patients across CF Teams & making forums part of the framework of therapy;

264. Emergent theme: It's advantageous to be in a group with others with CF-sharing of ideas/brainstorming;
265. Emergent theme: Feedback on PAR: People who have CF are better to give feedback on the framework than doctors;
266. Emergent theme: Feedback re sharing the framework with other CF patients at the Ottawa clinic: Yes, share;
267. Emergent theme: Ideas re dissemination of results: I think dissemination to counsellor/therapist vs patient should not be the same;
268. Emergent theme: Ideas re dissemination of results: for patients it could be a short video;
269. Emergent theme: Ideas re dissemination of results: if you want more information or for counsellors/therapists a published paper;
270. Emergent theme: Ideas re dissemination of results: create a national registry for CF groups/information session;
271. Emergent theme: Ideas re dissemination of results: a medical study journaled might produce more kickback in other clinics;
272. Emergent theme: Ideas re dissemination of results: have the information available on CF Canada website;
273. Emergent theme: Being involved has been valuable - it's appalling that there would ever be a framework just based on the science and not on individual people's experiences;
274. Emergent theme: Having this high and mighty well, we're going to study this from afar doesn't really make sense;
275. Emergent theme: You guys definitely need us - We're a different kind of sick-in the end I know my body and we know what we need even if you don't;
276. Emergent theme: It makes sense to be included - how can you get a good view of what's going on unless people who are experiencing it tell you;
277. Emergent theme: Our disease is a spectrum and bringing us into it makes sense;
278. Emergent theme: The fact that you had us involved from the beginning I actually believe you that you care about our answers and care about our opinion;
279. Emergent theme: People don't necessarily voluntarily tell people what they need, especially when it comes to counselling and mental health. It's good to have the practitioners encourage that out of us;

280. Emergent theme: I had a good experience being a co-facilitator, but I could have benefitted from more decisiveness regarding the expectation of the role;
281. Emergent theme: I really appreciated being involved in the framework, it was great facilitating and I got to share my thoughts too;
282. Emergent theme: In terms of this framework, it is crucial to bring in the nurse practitioners because they are fielding it for us;
283. Emergent theme: We should get clinic involved, let them learn from us so future patients can avoid our hiccups;
284. Emergent theme: Presenting the framework to the CF community would be a good way of communicating with each other;
285. Emergent theme: When disseminating the framework to patients there should be an infographic, a visual component then documentation attached;
286. Emergent theme: Disseminating the framework should be credible, substantive and really showcase the ground we covered;
287. Emergent theme: This focus group has allowed for us to talk together and connect in our experience;
288. Emergent theme: We have all found some common ground here-it's a really nice way to gain perspective;
289. Emergent theme: It's cool being in a video call where you can see and hear people coughing like you, but you don't have to mute yourself-you can just let it out;
290. Emergent theme: Group empathy and mutual support;
291. Emergent theme: This focus group has allowed for us to talk together and connect in our experience – I feel understood, valued and heard;
292. Emergent theme: This focus group has allowed for us to talk together and connect in our experience – I feel honoured to know all of you;
293. Emergent theme: It would be great to have an online forum to be able to connect as a CF community;
294. Emergent theme: There is an existing forum CF Ties;
295. Emergent theme: It would be nice to interact more with others with CF-here are the supports and connections;

296. Emergent theme: It's advantageous to be in a group with others with CF-sharing of ideas/brainstorming;
297. Emergent theme: I love everybody in this group and feel like I can reach out to you;
298. Emergent theme: There may be lots of coughing but that's part of the gig;
299. Emergent theme: Coughing on purpose during COVID to maintain bubbles - personal space - collective laughter;
300. Emergent theme: I do recognize a lot of what I'm going through in a lot of other people's explanations of things;
301. Emergent theme: I really resonate with a lot of your great points;
302. Emergent theme: This is amazing how you can relate to everyone's experience;
303. Emergent theme: A lot of things you guys said have resonated with me as well;
304. Emergent theme: It's really valuable being able to connect with each other;
305. Emergent theme: I have had a few unhelpful experiences and I think the catharsis of this might help;
306. Emergent theme: It's kinda like a therapy session - I feel like we're all going to wake up and exhale.

Section One: Semi-Structured Interviews Vertical Analysis

Notes for Charlene

1. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: The semi-structured interview allowed me to say a lot of the stuff that I didn't want to burden time on with the focus group;
2. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology -fostering a sense of community - Emergent theme: Focus group- hearing others helped me to think about how CF does impact our day to day;
3. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology -fostering a sense of community - Emergent theme: Focus group-the others' responses helped me to think about how CF has impacted me more than in the here and now;
4. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: CF had an

impact on family dynamics and relationships-not as much of an impact now but back in the day;

5. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: I used to fight a lot with my mom- she was very overprotective, and I was trying to be independent;
6. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: The concept of independence was a huge issue for me - my disease and my mother being overprotective meant that I didn't develop the skills;
7. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: The concept of independence was a huge issue for me - I didn't know if I had the skills because I was being taken care of;
8. Super-ordinate theme 2.b Psychological Impact of CF- emotional characteristics – Emergent theme: I was probably depressed - I was so unhappy with a lot of things in my life;
9. Super-ordinate theme 2.f Psychological Impact of CF- vulnerability versus control – Emergent theme: Pushing myself to change certain things I didn't like in my life gave me a sense of control and it empowered me;
10. Super-ordinate theme 2.b Psychological Impact of CF- emotional characteristics – Emergent theme: In the past I wasn't very social - I created opportunities to meet people which empowered me;
11. Super-ordinate theme 2.f Psychological Impact of CF- vulnerability versus control – Emergent theme: Once I started to exercise and saw a huge break in my health, I felt empowered, proud, a sense of control and happy;
12. Super-ordinate theme 2.f Psychological Impact of CF- vulnerability versus control – Emergent theme: There's a huge part of CF that isn't within your control and I accept that but learning that you can have some control/make a positive impact helped me;
13. Super-ordinate theme 1.e Experience living with CF day-to-day -illness/disability and healthcare bureaucracy – Emergent theme: Having to deal with disability and access to medications and fighting the bureaucracy of it all;

14. Super-ordinate theme 1.e Experience living with CF day-to-day -illness/disability and healthcare bureaucracy – Emergent theme: You have health issues and you're the one who must tie it all together which takes a lot of time and effort;
15. Super-ordinate theme 1.e Experience living with CF day-to-day -illness/disability and healthcare bureaucracy – Emergent theme: Having to deal with the administrative part all by yourself to try to get the proper health care all by yourself can be overwhelming when you're feeling sick;
16. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: You can kind of control when you tell people about your disability and how- passing;
17. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: If I needed the handicap parking space, I'd be worried about people keying my car. I can walk fine but that doesn't mean I can walk fine;
18. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: I worry that you could find yourself in conflict situations when you're sick and vulnerable;
19. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: There is a worry that if you're more sick you won't get the supports you need because people don't believe you;
20. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: I had a work experience where they didn't understand the severity of CF and they were not supportive at all;
21. Super-ordinate theme 1.c Experience living with CF day-to-day -impact on career – Emergent theme: Worry about changing jobs-will people be as supportive as my current direct supervisor;
22. Super-ordinate theme 1.c Experience living with CF day-to-day -impact on career – Emergent theme: Not every job context would understand how severe CF can be because I look fine externally, right;
23. Super-ordinate theme 1.c Experience living with CF day-to-day -impact on career – Emergent theme: I would not choose a job that is not willing to be flexible when I'm hospitalized/allow for priorities related to health;

24. Super-ordinate theme 1.c Experience living with CF day-to-day -impact on career – Emergent theme: Having to be discerning re suitability of employer - I would only choose a job where the environment is supportive to someone who gets sick a lot;
25. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Be easily accessible;
26. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills - Emergent theme: Ensure that there is a connection and follow up;
27. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Being told you're not dying so it's okay makes me feel worse;
28. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Don't assume that if someone seems physically okay, they're mentally doing okay;
29. Super-ordinate theme 1.e Experience living with CF day-to-day -illness/disability and healthcare bureaucracy – Super-ordinate theme Emergent theme: Being in the grey zone (middle ground between healthy and not healthy), means that you fall through the cracks, and you don't get the support you need - medical care;
30. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: What I want to avoid is you not doing anything because I'm not sick enough. Follow up sooner, re-evaluate as my health evolves;
31. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: Making the most of the time that you have;
32. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: CF has given me an outlook so that I am able to let go of things easily;
33. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: CF has allowed me to appreciate more every moment;
34. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: It's important to appreciate everything that life has to offer, which includes overcoming challenges;

35. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: I don't need fake validation of my strengths. I prefer an empathetic, solution focused action plan;
36. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Get informed about what CF is;
37. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Understand that physical health does not necessarily reflect mental health and vice versa;
38. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Have some sort of existential discussion on what CF means/the meaning of life as CF touches on death and mortality, where appropriate;
39. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Each CF patient has different experiences, different needs and are at different stages. Focus on whatever aspect of their life they need.

Notes for Kyle

1. Super-ordinate theme 2.f Psychological impact of CF – vulnerability versus control/ 4. CF positive aspects and meaning and purpose in life – Emergent theme: Finding fun and interest, maybe meaning too with Phages;
2. Super-ordinate theme 2.f Psychological impact of CF – vulnerability versus control/ 4. CF positive aspects and meaning and purpose in life – Emergent theme: "A sense of meaning and purpose in life": Phages;
3. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community -Emergent theme: Thank you for bringing awareness to this cause otherwise I wouldn't have known other people going through transplant;
4. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Share some stories of others with CF to open up the doors for a conversation. Would help me to reflect upon my own journey/experience;

5. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Hearing others' stories impactful on an emotional level. Can help you prepare for eventualities such as a lung transplant;
6. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills - Emergent theme: Integrating mental health at CF clinic appointments: telling other people's stories brings more of an all-encompassing aspect to our CF experience (medications, emotions, relationships). Using stories and narratives;
7. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: The medical system is all about the physical aspects such as medications but what about the metaphysical aspects - mental preparation for medications, mental blockers for relationships and activities. That was missing;
8. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Integrating mental health at CF clinic appointments: normalize challenges/seeing a therapist and give some examples of others with CF that might resonate;
9. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: The medical system is all about the physical aspects such as medications but what about the metaphysical aspects - therefore, I'm fine I'm fine;
10. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Share some stories of others with CF. It might resonate with us. I'm the same;
11. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships – Emergent theme: Family stigma regarding therapy-until I impressed upon mum how much CF impacts intimacy;
12. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships – Emergent theme: CF effects my lung capacity and my ability to be intimate with a partner;

13. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Knowledge of other disabilities/illnesses and how these are ported over to CF;
14. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: Being able to talk about CF more openly more freely and then having a sense of more self-worth;
15. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: The conditions of therapy, where somebody understands, and listens helps to open up to others later on;
16. Super-ordinate theme 1.a Experience living with CF day-to-day- symptoms & treatments (pre and post Trikafta) – Emergent theme: Experience of CF day-to -day can be broken down to pre and post Trikafta;
17. Super-ordinate theme 1.a Experience living with CF day-to-day- symptoms & treatments (pre and post Trikafta) – Emergent theme: Experience of CF post Trikafta: Finding excitement in renewed abilities;
18. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Helpful and important elements - intro meditation, writing down and referencing notes, recommending materials, where are we now and where do we go from here/goal setting;
19. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Having a co-facilitator with CF, gave everybody equal opportunity to speak their mind and bringing his own experience to the table was very good;
20. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Having a co-facilitator with CF, bringing his own experience in was very good. It kept things flowing like you're writing a paragraph;
21. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Having a co-facilitator with CF, bringing his own experience may have given it a bit more flow and felt a bit more comfortable;

22. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results -Emergent theme: five-minute questionnaires spread out over clinic appointments to get information on the impact of CF on people's lives over time. An explanation after and a post follow up;
23. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results -Emergent theme: five-minute questionnaires can also help people who don't realize what's going on or feel like they're alone.

Notes for Alice

1. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments – Emergent theme: Feeling good is relative;
2. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Focus group/connecting with people with CF completely life changing;
3. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Focus groups helped people to connect and have a sense of community;
4. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day -symptoms & treatments – Emergent theme: The impact of CF has changed over time;
5. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments - Emergent theme: Now CF can be restrictive;
6. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day -symptoms & treatments – Emergent theme: CF now requires proper time management to make time for treatments;
7. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: CF is a mental battle;
8. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: It's hard to accept where I am;
9. Super-ordinate theme 1.h Experience living with CF (RD) day-to-day- CF and the impact of COVID – Emergent theme: My roommates have to take extreme measures to keep me safe;

10. Super-ordinate theme 2.c Psychological Impact of CF(RD)- the role of others -Emergent theme: Others keeping me safe is sometimes a difficult burden;
11. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control - Emergent theme: Teetering the line between normal and not normal;
12. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: Teetering that line between healthy and like not sick person (chronic illness and not living with chronic illness);
13. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: Trying to balance my own expectations of myself with others' expectations of myself;
14. Super-ordinate theme 1.h Experience living with CF (RD) day-to-day- CF and the impact of COVID – Emergent theme: Having to manage people's expectations of getting together with being safe;
15. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships - Emergent theme: Balancing my own expectations of myself and also the expectations of others. Guilt and resentment;
16. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: CF can be a struggle. There's way less wiggle room to be a regular human being;
17. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: It's really difficult when you're at the bottom of it;
18. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: The downturn in my health has taken a real emotional toll;
19. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control - Emergent theme: I feel guilty. Did I somehow stop caring for myself? Can I be back there;
20. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control - Emergent theme: Feeling like you can control the quality of your life or that you can't. What the heck is it going to take to get there;
21. Super-ordinate theme1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: I'm more concerned about the impact of CF on others more than on me;

22. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships - Emergent theme: Having to have big conversations (around life expectancy and having biological children) that put future stress on relationships;
23. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day -symptoms & treatments – Emergent theme: Fluctuating nature of illness takes a toll on our day-to-day life and roles;
24. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: Having to deal with the judgements and assumptions of others;
25. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: Having to disclose something personally embarrassing about the workings of my body to my employer;
26. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: CF as a non-visible disability-completely impacted my work;
27. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: CF as a non-visible disability makes you question is this what the work world is like? No. That was a toxic work environment;
28. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life -Emergent theme: It gave me a sense of meaning and purpose to be super impactful to lots of people;
29. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: To completely demonstrate all the positive things we can still do/the difference we can make;
30. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: Being impactful being able to tell my story. A privilege. I've literally loved it;
31. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: The visualization of someone pulling like a demon out of me;
32. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: Giving feedback about positive progress;
33. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: Genuine and rich encounters (light bulb moments);

34. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: Therapy helps me to process my CF. All the aspects of it. Helps me in the day to day;
35. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: Therapy has helped me to change my internal dialogue;
36. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: Being in a calm vulnerable state allows things to "ooze out;"
37. Super-ordinate theme 2. b Psychological Impact of CF (RD)- emotional characteristics/6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Recognize that all of us living with chronic illness need mental health help/therapy: I had this dark thing inside of me;
38. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Be well educated, encourage self-reflection, active listening, reflecting, some transparency so that we're both human/less hierarchical;
39. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Educational background is important;
40. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Putting us at that same level makes sense;
41. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Someone who understands not only chronic illness but specifically CF;
42. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Someone who understands not only chronic illness but specifically CF (We're grappling with this big underlying issue that's impacting all of our experiences);
43. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Talking about working with others with chronic illness opens up space for those conversations;

44. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Starting off with a grounding meditation;
45. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Take aways. For example, work sheets, that match client needs and can be applied to everything, tangible resources and exercises, book recommendations. “Lessons don’t happen just in the office;”
46. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills/6.b Observations and recommendations for CF (RD) doctors, nurses and all allied health-integrating mental health – Emergent theme: Everyone on the health care team needs to be on the same page (including mental health);
47. 6.b Observations and recommendations for CF (RD) doctors, nurses and all allied health-integrating mental health – Emergent theme: Everyone on the health care team needs to be on the same page (including mental health). In cahoots. They fit in the bigger picture;
48. 6.b Observations and recommendations for CF (RD) doctors, nurses and all allied health-integrating mental health – Emergent theme: Communication with mental health and vice versa is important (re counselling framework and having doctors teach you how to take care of yourself);
49. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Focus groups helped people to connect and have a sense of community;
50. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Video communications (MS Teams) took the judgement out of it so people could speak more freely than face to face;
51. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Maybe speaking with the support systems of people with CF. Seeing their perspective on how we struggle with it;
52. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Looking at how people (family?) can support people with chronic illness better;

53. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: There is a resentment from siblings;
54. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Looking at how parents' who raise their person with chronic illness-how their decisions impact us. Shape our mindsets;
55. Super-ordinate theme 2. b Psychological Impact of CF (RD)- emotional characteristics/8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: We all end up with different complexes;
56. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Sharing the results with others with CF is important. We're a collective. Finalizing it and then giving us kind of the first view of it;
57. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Focus groups helped develop a sense of community: we are a collective;
58. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Sharing the results with others with CF is important. We're a collective. Ultimately, it's to help our whole community, not just the group of us who are OK in therapy;
59. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Sharing the results with others with CF is important. Even if it's opening a dialogue;
60. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Integrating social support into our health care picture. Emphasizing the resources for counselling and the importance of it;
61. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Some sort of ramp up process re therapy (for some can be intimidating). A little bit of taste but not overwhelming;

62. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Therapy onboarding. When people express interest and also when they switch to adult clinic;
63. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Therapist to learn about the big themes. Onboarding for therapists;
64. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Therapy onboarding for CFers. CHEAT SHEET re common things we all feel. Share this with patients. I am not alone.

Notes for Jake

1. Super-ordinate theme 1.a Experience living with CF (RD) day-to-day- symptoms & treatments -Emergent theme: Pre-transplant-life revolved around physiotherapy & treatment routines;
2. Super-ordinate theme 1.a Experience living with CF (RD) day-to-day- symptoms & treatments -Emergent theme: Post- transplant: No more physio day and night;
3. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life – Emergent theme: Sometimes I felt sorry for myself but I persevered;
4. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life – Emergent theme: You're willing to do a lot to live;
5. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability- Emergent theme: Being challenged because I may not look like I belong in a handicapped parking spot;
6. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability- Emergent theme: I don't really feel like I have to explain myself, but I also don't want to abuse it (handicapped parking spot);
7. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: One on one talking and the focus group was good, but I could only do these as needed because I am pressed for time;
8. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Feedback re Focus group - Choosing confrontations carefully;

9. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Feedback re Focus Group - unsolicited advice from someone who is not an expert in the field;
10. Super-ordinate theme 1.c Experience living with CF (RD) day-to-day -impact on career – Emergent theme: Having to make vocational choices based on access to healthcare coverage;
11. Super-ordinate theme 5. CF (RD) and sense of self/Identity – Emergent theme: Violation of trust, privacy and not being able to control your own narrative regarding having CF;
12. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability/ 5. CF (RD) and sense of self/Identity – Emergent theme: I would have chosen concealment/to have been treated like everyone else;
13. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability/ 5. CF (RD) and sense of self/Identity – Emergent theme: I didn't want them to know I had CF- I didn't want to be judged based on my illness;
14. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability/ 5. CF (RD) and sense of self/Identity – Emergent theme: I didn't want to be identified as J with cystic fibrosis;
15. Super-ordinate theme 5. CF (RD) and sense of self/Identity – Emergent theme: Like Pinocchio, you want to be a real boy;
16. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics/5. CF (RD) and sense of self/Identity – Emergent theme: I was ashamed of CF. I felt like I was a burden on society;
17. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics/5. CF (RD) and sense of self/Identity – Emergent theme: As I grew older, I realized CF is not my fault. Genetics;
18. Super-ordinate theme1.b Experience living with CF (RD) day-to-day- interpersonal relationships – Emergent theme: My shame around CF has to do with my mother;
19. Super-ordinate theme1.b Experience living with CF (RD) day-to-day- interpersonal relationships – Emergent theme: My father thought of me as a gift;
20. Super-ordinate theme 2.c Psychological Impact of CF (RD) - the role of others/ 5. CF (RD) and sense of self/Identity – Emergent theme: Conflicted feelings. Because of me this is our family;

21. Super-ordinate theme 2.c Psychological Impact of CF (RD) - the role of others/ 4. CF (RD) positive aspects and meaning and purpose in life/ 5. CF (RD) and sense of self/Identity – Emergent theme: I'm going to bankrupt this family;
22. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life - Emergent theme: I might be disabled but I'm capable - we just want to become a productive member of society;
23. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life/5. CF (RD) and sense of self/Identity - Emergent theme: I didn't want to be judged based on my illness: I'm better than just a sick kid;
24. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life/ 5. CF (RD) and sense of self/Identity - Emergent theme: I have CF but there's so much more to me;
25. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life - Emergent theme: CF has caused me to prioritize: if this is my last day on earth how do I want to spend it;
26. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability- Emergent theme: Growing up it was my dirty little secret;
27. Super-ordinate theme 2.a Psychological Impact of CF (RD) - Stigma/ 3. CF (RD) as a non-visible illness/disability- Emergent theme: It's not such a stigmatized thing anymore;
28. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability- Emergent theme: Concealment was important when looking for a mate in my twenties but less important now that I have all sorts of great things;
29. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability- Emergent theme: It's better now to disclose, to put your cards on the table;
30. Super-ordinate theme 2.e Psychological Impact of CF (RD) - isolation from others with CF – Emergent theme: You feel like you're living in a bubble, like you're the only person in the world with CF;
31. Super-ordinate theme 2.e Psychological Impact of CF (RD) - isolation from others with CF/2.f Psychological Impact of CF (RD) – vulnerability versus control – Emergent theme: Finding other people with CF you can relate to helps to feel less in a bubble;

32. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics - Emergent theme: I was a mess waiting for my lung transplant. I was worried and scared and anxious;
33. Super-ordinate theme 2.f Psychological Impact of CF (RD) – vulnerability versus control/ 4. CF (RD) positive aspects and meaning and purpose in life/ 5. CF (RD) and sense of self/Identity – Emergent theme: While waiting for a lung transplant I was starting to come to terms with my CF. I made a blog about my life;
34. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns - Emergent theme: Suddenly I had a whole community of friends
35. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns - Emergent theme: I lost many friends;
36. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics/ 2.f Psychological Impact of CF (RD) – vulnerability versus control – Emergent theme: When someone passes away from CF you're very depressed and anxious and it causes you to take stock;
37. Super-ordinate theme 2.e Psychological Impact of CF (RD) - isolation from others with CF – Emergent theme: Others with CF feel like family due to common struggles;
38. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns – Emergent theme: You think you'd be desensitized but every death took a toll on me;
39. Super-ordinate theme 1.b Experience living with CF (RD) day-to-day- interpersonal relationships/ 2. d Psychological Impact of CF (RD) - transplant experience and existential concerns – Emergent theme: I don't want to get too close to others with CF lest I lose them again;
40. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns/ 2.f Psychological Impact of CF (RD) – vulnerability versus control – Emergent theme: Looking for hints and clues. What did the ones who died from lung transplants do wrong;
41. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics - Emergent theme: Psychological impact of waiting for a transplant- You start concocting all these paranoid theories;

42. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Hear me out and then be frank and reflect back the reality of what's actually happening;
43. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: It could help you to get past your fears and theories and see the reality;
44. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: It is helpful to give me scientific explanations about what's happening in my brain. I'm reassured by science;
45. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns – Emergent theme: Grappling with existential death anxiety;
46. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns – Emergent theme: Knowing that energy doesn't dissipate but changes form helped me to feel reassured about death;
47. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Being non-judgmental would help me to talk openly;
48. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Provide a bit of factual evidence to reassure me when I'm spinning out;
49. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Hear me out and then be frank and reflect back the reality of what's actually happening;
50. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: It is helpful to give me scientific explanations about what's happening in my brain. I'm reassured by science;
51. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: It can't hurt if you have a background in CF;
52. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: It would be very important to understand that CFers live with a lot of fear and uncertainty about the future;

53. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: I don't need your false empathy;
54. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Genuine and active listening to my experience works;
55. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Active listening is good;
56. Super-ordinate theme 6.b Observations and recommendations for CF (RD) doctors, nurses and all allied health – Emergent theme: Frank answers/be direct vs we don't know what it could be.

Notes for Karen

1. Super-ordinate theme 1.f Experience living with CF day-to-day-Significant cognitive impact – Emergent theme: We have to think in terms of time management and possible scenarios;
2. Super-ordinate theme 1.f Experience living with CF day-to-day-Significant cognitive impact – Emergent theme: Hyper planning and controlling over our space;
3. Super-ordinate theme 1.f Experience living with CF day-to-day-Significant cognitive impact – Emergent theme: Having to maintain vigilance in public places (think worse case scenarios/risk management/hyper-planners);
4. Super-ordinate theme 1.g Experience living with CF day-to-day- Existential responsibility – Emergent theme: It's a load that we carry willingly because it's our lives;
5. Super-ordinate theme 1.b 8.a Experience living with CF day-to-day- interpersonal relationships – Emergent theme: It's hard to communicate the fluctuations of it;
6. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: You have created a respectful space/we feel heard, so that is why you have gotten the feedback that you have. We are trusting you with what our future will look like. Respect is two ways;

7. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: The only way to work with the disease that's a spectrum is to talk to people who are on that spectrum;
8. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: An experience-based approach is more respectful to the disability community. Grassroots;
9. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results/ 8.b Feedback and suggestions re: PAR methodology – fostering a sense of community – Emergent theme: I left the conversation on such a high, speaks to the potential of a virtual therapy environment for CF patients;
10. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: I went from being angry about my disease and my future prospects to gain an expanded perspective as to how my disease informs my life. A transformational experience;
11. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health _Emergent theme: Create a safe space so no matter at what stage you are at you share your piece;
12. Super-ordinate theme 1.g Experience living with CF day-to-day- Existential responsibility - Emergent theme: You are the determinant of how well your lungs do;
13. Super-ordinate theme 2.f Psychological Impact of CF- vulnerability versus control - Emergent theme: You are your fiercest advocate and the master of your destiny;
14. Super-ordinate theme 3. CF as a non-visible illness/disability - Emergent theme: Having to teach non -CF doctors what our disease entails;
15. Super-ordinate theme 3. CF as a non-visible illness/disability - Emergent theme: Having to fight to get my CF meds. You don’t look sick;
16. Super-ordinate theme 3. CF as a non-visible illness/disability - Emergent theme: They don’t believe me. You don’t look sick;
17. Super-ordinate theme 2.c Psychological Impact of CF- the role of others/ 3. CF as a non-visible illness/disability – Emergent theme: The trauma of having to justify my illness;
18. Super-ordinate theme 1.d Experience living with CF day-to-day- CF as spectrum - Emergent theme: The notion of the disease itself as a spectrum;

19. Super-ordinate theme 1.d Experience living with CF day-to-day- CF as spectrum - Emergent theme: There are some of us who have very different experiences;
20. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships – Emergent theme: It's hard to communicate the fluctuations of it;
21. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: Just because I look like I'm carrying this well doesn't mean it's not heavy;
22. Super-ordinate theme 2.b Psychological Impact of CF-emotional characteristics – Emergent theme: We carry that load;
23. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships – Emergent theme: The whole spectrum of the disease makes it's hard for us to let other people into the conversation and ask for support;
24. Super-ordinate theme1.b Experience living with CF day-to-day- interpersonal relationships/ 2.c Psychological Impact of CF- the role of others - Emergent theme: It reverts to keeping it inside;
25. Super-ordinate theme 2.b Psychological Impact of CF-emotional characteristics -Emergent theme: It's very heavy to carry;
26. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: Concealment vs. disclosure-you never know when to fully open with someone;
27. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: Having to fight to get my CF meds. You don't look sick;
28. Super-ordinate theme 5. CF and sense of self/Identity – Emergent theme: I'm more than the dying friend;
29. Super-ordinate theme 2.c Psychological Impact of CF- the role of others/ 3. CF as a non-visible illness/disability – Emergent theme: The trauma of having to justify my illness;
30. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: CF has taught me the importance of compassion and empathy;
31. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: CF has made me cognisant of people's need to be heard, seen, supported;
32. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: CF has fueled my fire to go forward and defy ceilings;

33. Super-ordinate theme 1.a Experience living with CF day-to-day- symptoms & treatments/ 2.b Psychological Impact of CF-emotional characteristics/ 4. CF positive aspects and meaning and purpose in life – Emergent theme: We mature very quickly;
34. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: As much as I've been through what gave me back my meaning was my nephew, the joy of being present for his life;
35. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: We don't live in a Fantasyland but there is still joy in moments;
36. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Therapists need to have a balance of the light and the dark;
37. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Read the room. We don't need you to cheer us up. We need you to get us moving;
38. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Focusing on tangible components. Here's my issue. Let's break it down;
39. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: How can I best support you in this session? If you ask that question and then deliver that engenders trust. CFers feel heard and seen;
40. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Understanding CF from a variety of standpoints;
41. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: As much exposure to the various spectrums of our disease would be an asset;
42. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Sit in at clinic appointments to get a sense of what questions we are asked regularly;

43. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Knowledge of the CF experience including clinic and PFTs, means a lot;
44. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: It's important to have exposure to patients on lung transplant list, to pulmonary function tests, join in CF Canada events to meet families;
45. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Knowing some medication names. Knowledge of CF in all its aspects;
46. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Base level understanding about medications/treatment protocols;
47. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Have an understanding about applications for medication/very stressful process for patients;
48. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Understand your patient's specific treatment regime/can help with context. How can we mitigate, how can we help you from a mental health standpoint;
49. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Help us to mitigate the treatment load from a mental health perspective. Self-care;
50. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Understanding treatment (individual regimens), key words. From hierarchical relationship to walking beside;
51. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Keep us moving. Also, discern what to stick with and when to move forward (do this constructively);

52. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Be very skillful and tactful about transitions and time keeping. Be transparent. Establishes trust;
53. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Be transparent: this is what I mean by that;
54. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Sharing/therapist self-disclosure builds trust;
55. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Respect boundaries (know where you can push and where you cannot). Be transparent. Have a dialogue;
56. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Don't put me in a box. My mental health may be impacted by environmental factors not just my CF;
57. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Virtual sessions, collaborative goal setting (one thing), relevant homework. Takeaways, Timekeeping;
58. Super-ordinate theme 2.c Psychological Impact of CF- the role of others – Emergent theme: An internalized fear of abandonment;
59. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships/ 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: We don't want to burden people if we start to decline. Sticking with us means a lot;
60. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health -Emergent theme: Understand that CF is emotionally heavy. Once you earn our trust, we're in it for the long haul;
61. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills - Emergent theme: Understand the issues we are up against (help us to work through emotions re fertility, contemplating whether or not to be mothers);

62. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills - Emergent theme: Help us to work through how our bodies function;
63. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Having support in clinic from a mental and emotional side would help with the transition to adult clinic;
64. Super-ordinate theme 2.c Psychological Impact of CF- the role of others - Emergent theme: The transition from Pediatrics to Adult clinic there's immense anxiety and panic because you now have to advocate for yourself;
65. Super-ordinate theme 2.c Psychological Impact of CF- the role of others - Emergent theme: A lot of pressure to get it all in once/four months and for transitioning patients to now advocate for themselves;
66. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: The social work position should be full time (we don't want to share you with other clinics);
67. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Therapy sessions outside clinic hours would be helpful;
68. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Offer options for mental health support/therapy outside of clinic hours;
69. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Have the option of either one to one sessions or groups;
70. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Have the option of either one to one sessions or groups. Time slots for both, different groups;
71. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: One to one sessions virtual or in person. Keep the options open;

72. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Any groups need to be structured with social worker/therapist (we're all a bit socially awkward);
73. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: It's a grey area communicating outside of clinic-offer structured groups where people can find community and social connection;
74. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Including patients crucial in both formats (focus groups and one to one interviews);
75. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Include nurse practitioner, she knows how clinic operates (context);
76. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Make sure to include patients from different age groups/different perspectives;
77. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Routing it in experience contextualizes and disproves the stereotype;
78. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Important to think through the strategy re dissemination of results;
79. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Making knowledge accessible to different types of learners re dissemination of results;
80. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Dissemination of results (innovation and creativity).

Notes for Veronica

1. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results/ 8.b Feedback and suggestions re: PAR

methodology - fostering a sense of community – Emergent theme: PAR focus groups are helpful. People feed off one another-you'll have something to add that you might not of thought of or remembered;

2. Super-ordinate theme 2.e Psychological Impact of CF(RD)- isolation from others with CF/ 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: That was a different and good experience for me talking to others with CF, similar experiences, perspectives;
3. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Semi-structured interviews you can build on what you had to say. More in-depth and personal;
4. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments – Emergent theme: Integrating new treatments-remembering and finding the Mental Space;
5. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments – Emergent theme: adding new treatments- feels worse mentally- am I getting worse?;
6. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments – Emergent theme: Treatments – being tired, using more physical and mental energy then people without CF;
7. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: Worrying about how your family is feeling and the medications;
8. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: I think about how family thinks and feels before my own thoughts and feelings;
9. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: I kept my problems with CF, school to myself so as not to worry my family;
10. Super-ordinate theme 2.b Psychological Impact of CF(RD)-emotional characteristics - Emergent theme: Mix of education and CF contributed to burnout;

11. Super-ordinate theme 1.c Experience living with CF(RD) day-to-day –impact on career/education/life path – Emergent theme: There are limits of what I can do – career, education, travel;
12. Super-ordinate theme 1.c Experience living with CF(RD) day-to-day –impact on career/education/life path – Emergent theme: Fluctuating nature has an impact on education, socially;
13. Super-ordinate theme 1.c Experience living with CF(RD) day-to-day –impact on career/education/life path – Emergent theme: Fluctuating nature of CF has an impact on education and mental health;
14. Super-ordinate theme 2.a Psychological Impact of CF(RD)-stigma – Emergent theme: Pushing the CF side back led to burnout;
15. Super-ordinate theme 1.c Experience living with CF(RD) day-to-day –impact on career/education/life path – Emergent theme: I was trying to be as normal as possible. Passing;
16. Super-ordinate theme 1.c Experience living with CF(RD) day-to-day –impact on career/education/life path - Emergent theme: I have CF but I have the same life expectations as everyone else to follow the normal life path;
17. Super-ordinate theme 1.h Experience living with CF (RD) day-to-day- CF and the impact of COVID – Emergent theme: COVID gave me time to breath/gave me a break- from expectations;
18. Super-ordinate theme 1.h Experience living with CF (RD) day-to-day- CF and the impact of COVID – Emergent theme: COVID gave me a break from getting sick;
19. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: You look fine;
20. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: Work is understanding to a normal person point-missing work;
21. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life – Emergent theme: It's made me care less about the unimportant things (for example, drama in relationships) CF has given me perspective;

22. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life – Emergent theme: CF has given me perspective-life is short therefore I want to focus on things I want to do;
23. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life/ 5. CF(RD) and sense of self/Identity – Emergent theme: CF has given me perspective-why waste energy on drama;
24. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: Therapy has made me more comfortable talking about myself;
25. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: Therapy has helped me to have more insight into my psychological processes and how to cope;
26. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Therapist attitudes that are important for me to talk openly - supportive and non-judgemental;
27. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Therapist attitudes that are important for me to talk openly - supportive and non-judgemental. Non-verbal too;
28. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Understand the underlying reason for a behavior rather than judging (in this case, procrastination);
29. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: The ability to ask questions, especially if someone is new to therapy;
30. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Helping me find the words to describe my emotions and the ability to cope and deal with those;
31. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Help me to realize what's on my mind/gain insight and what to do with that;
32. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: When patients are new

to therapy-focusing on topics they are comfortable with at first. Getting the ball rolling conversationally. Building rapport and trust;

33. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Knowledge of anxiety and depression as well as techniques to help patient in the moment and techniques to teach patient healthy coping mechanisms;
34. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills/ 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: More of a presence from a younger age. Normalization of the impact of CF on mental health. Also, for caregivers;
35. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills/ 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Pop your head in at appointments. How's it going? I see you were sick here. Did that impact anything;
36. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Non-judgement. Look at underlying causes to non-compliance. Maybe there are some mental health issues behind it;
37. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Sharing the results with others with CF would yield a more accurate product;
38. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Suggestions for Disseminating results: Pamphlet and written article;
39. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: A positive impact of publishing an article in a medical journal- educate doctors about the experience of having CF/ less judgemental.

Section Two: Semi-Structured Interviews Horizontal Analysis

1. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: The semi-structured interview allowed me to say a lot of the stuff that I didn't want to burden time on with the focus group;
2. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Semi-structured interviews you can build on what you had to say. More in-depth and personal;
3. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Focus groups helped people to connect and have a sense of community;
4. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results/ 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: PAR focus groups are helpful. People feed off one another-you'll have something to add that you might not of thought of or remembered;
5. Super-ordinate theme 2.e Psychological Impact of CF(RD)- isolation from others with CF/ 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: That was a different and good experience for me talking to others with CF, similar experiences, perspectives;
6. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community -Emergent theme: Thank you for bringing awareness to this cause otherwise I wouldn't have known other people going through transplant;
7. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Focus group/connecting with people with CF completely life changing;
8. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Focus groups helped people to connect and have a sense of community;
9. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results/ 8.b Feedback and suggestions re: PAR

methodology – fostering a sense of community – Emergent theme: I left the conversation on such a high, speaks to the potential of a virtual therapy environment for CF patients;

10. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology -fostering a sense of community - Emergent theme: Focus group- hearing others helped me to think about how CF does impact our day to day;
11. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Share some stories of others with CF to open up the doors for a conversation. Would help me to reflect upon my own journey/experience;
12. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Feedback re Focus Group - unsolicited advice from someone who is not an expert in the field;
13. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results/ 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: PAR focus groups are helpful. People feed off one another-you'll have something to add that you might not of thought of or remembered;
14. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Having a co-facilitator with CF, bringing his own experience may have given it a bit more flow and felt a bit more comfortable;
15. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: You have created a respectful space/we feel heard, so that is why you have gotten the feedback that you have. We are trusting you with what our future will look like. Respect is two ways;
16. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: The only way to work with the disease that's a spectrum is to talk to people who are on that spectrum;
17. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Sharing the results with others with CF would yield a more accurate product;

18. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Therapy onboarding. When people express interest and also when they switch to adult clinic;
19. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Therapy onboarding for CFers. CHEAT SHEET re common things we all feel. Share this with patients. I am not alone;
20. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results -Emergent theme: five-minute questionnaires spread out over clinic appointments to get information on the impact of CF on people's lives over time. An explanation after and a post follow up;
21. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results -Emergent theme: five-minute questionnaires can also help people who don't realize what's going on or feel like they're alone;
22. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health _Emergent theme: Create a safe space so no matter at what stage you are at you share your piece;
23. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Suggestions for Disseminating results: Pamphlet and written article;
24. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: Therapist to learn about the big themes. Onboarding for therapists;
25. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results – Emergent theme: A positive impact of publishing an article in a medical journal- educate doctors about the experience of having CF/ less judgemental.
26. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Include nurse practitioner, she knows how clinic operates (context);

27. Super-ordinate theme 8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results - Emergent theme: Making knowledge accessible to different types of learners re dissemination of results;
28. Super-ordinate theme 2.b Psychological Impact of CF- emotional characteristics – Emergent theme: I was probably depressed - I was so unhappy with a lot of things in my life;
29. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: The concept of independence was a huge issue for me - my disease and my mother being overprotective meant that I didn't develop the skills;
30. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: CF had an impact on family dynamics and relationships-not as much of an impact now but back in the day;
31. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: I used to fight a lot with my mom- she was very overprotective, and I was trying to be independent;
32. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships-autonomy/independence from family of origin - Emergent theme: The concept of independence was a huge issue for me - I didn't know if I had the skills because I was being taken care of;
33. Super-ordinate theme 2.f Psychological Impact of CF- vulnerability versus control – Emergent theme: Pushing myself to change certain things I didn't like in my life gave me a sense of control and it empowered me;
34. Super-ordinate theme 2.f Psychological Impact of CF- vulnerability versus control – Emergent theme: Once I started to exercise and saw a huge break in my health, I felt empowered, proud, a sense of control and happy;
35. Super-ordinate theme 2.b Psychological Impact of CF- emotional characteristics – Emergent theme: In the past I wasn't very social - I created opportunities to meet people which empowered me;

36. Super-ordinate theme 1.e Experience living with CF day-to-day -illness/disability and healthcare bureaucracy – Emergent theme: Having to deal with disability and access to medications and fighting the bureaucracy of it all;
37. Super-ordinate theme 1.e Experience living with CF day-to-day -illness/disability and healthcare bureaucracy – Emergent theme: You have health issues and you're the one who must tie it all together which takes a lot of time and effort;
38. Super-ordinate theme 1.e Experience living with CF day-to-day -illness/disability and healthcare bureaucracy – Emergent theme: Having to deal with the administrative part all by yourself to try to get the proper health care all by yourself can be overwhelming when you're feeling sick;
39. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: Making the most of the time that you have;
40. Super-ordinate theme 3. CF as a non-visible illness/disability – Emergent theme: If I needed the handicap parking space, I'd be worried about people keying my car. I can walk fine but that doesn't mean I can walk fine;
41. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: CF has given me an outlook so that I am able to let go of things easily;
42. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: CF has allowed me to appreciate more every moment;
43. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: It's important to appreciate everything that life has to offer, which includes overcoming challenges;
44. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: I don't need fake validation of my strengths. I prefer an empathetic, solution focused action plan;
45. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships – Emergent theme: Family stigma regarding therapy-until I impressed upon mum how much CF impacts intimacy;
46. Super-ordinate theme 2.f Psychological impact of CF – vulnerability versus control/4. CF positive aspects and meaning and purpose in life – Emergent theme: Finding fun and interest, maybe meaning too with Phages;

47. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills - Emergent theme: Integrating mental health at CF clinic appointments: telling other people's stories brings more of an all-encompassing aspect to our CF experience (medications, emotions, relationships). Using stories and narratives;
48. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Share some stories of others with CF to open up the doors for a conversation. Would help me to reflect upon my own journey/experience;
49. Super-ordinate theme 8.b Feedback and suggestions re: PAR methodology - fostering a sense of community – Emergent theme: Hearing others' stories impactful on an emotional level. Can help you prepare for eventualities such as a lung transplant;
50. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Knowledge of other disabilities/illnesses and how these are ported over to CF;
51. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: Being able to talk about CF more openly more freely and then having a sense of more self-worth;
52. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: The conditions of therapy, where somebody understands, and listens helps to open up to others later on;
53. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: CF is a mental battle;
54. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: It's really difficult when you're at the bottom of it;
55. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments - Emergent theme: Now CF can be restrictive;
56. Super-ordinate theme 1.h Experience living with CF (RD) day-to-day- CF and the impact of COVID – Emergent theme: My roommates have to take extreme measures to keep me safe;

57. Super-ordinate theme 2.c Psychological Impact of CF(RD)- the role of others -Emergent theme: Others keeping me safe is sometimes a difficult burden;
58. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: Having to deal with the judgements and assumptions of others;
59. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: CF as a non-visible disability-completely impacted my work;
60. Super-ordinate theme 3. CF(RD) as a non-visible illness/disability – Emergent theme: CF as a non-visible disability makes you question is this what the work world is like? No. That was a toxic work environment;
61. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control - Emergent theme: I feel guilty. Did I somehow stop caring for myself? Can I be back there;
62. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control - Emergent theme: Feeling like you can control the quality of your life or that you can't. What the heck is it going to take to get there;
63. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life -Emergent theme: It gave me a sense of meaning and purpose to be super impactful to lots of people;
64. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life – Emergent theme: To completely demonstrate all the positive things we can still do/the difference we can make;
65. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: Being impactful being able to tell my story. A privilege. I've literally loved it;
66. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences - Emergent theme: The visualization of someone pulling like a demon out of me;
67. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics/5. CF (RD) and sense of self/Identity – Emergent theme: I was ashamed of CF. I felt like I was a burden on society;
68. Super-ordinate theme1.b Experience living with CF (RD) day-to-day- interpersonal relationships – Emergent theme: My shame around CF has to do with my mother;
69. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability/ 5. CF (RD) and sense of self/Identity – Emergent theme: I didn't want them to know I had CF- I didn't want to be judged based on my illness;

70. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life - Emergent theme: I might be disabled but I'm capable - we just want to become a productive member of society;
71. Super-ordinate theme 5. CF (RD) and sense of self/Identity – Emergent theme: Like Pinocchio, you want to be a real boy;
72. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life/5. CF (RD) and sense of self/Identity - Emergent theme: I didn't want to be judged based on my illness: I'm better than just a sick kid;
73. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life/ 5. CF (RD) and sense of self/Identity - Emergent theme: I have CF but there's so much more to me;
74. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life - Emergent theme: CF has caused me to prioritize: if this is my last day on earth how do I want to spend it;
75. Super-ordinate theme 2.e Psychological Impact of CF (RD) - isolation from others with CF – Emergent theme: You feel like you're living in a bubble, like you're the only person in the world with CF;
76. Super-ordinate theme 2.e Psychological Impact of CF (RD) - isolation from others with CF/ 2.f Psychological impact of CF (RD) – vulnerability versus control – Emergent theme: Finding other people with CF you can relate to helps to feel less in a bubble;
77. Super-ordinate theme 2.b Psychological Impact of CF(RD) - emotional characteristics - Emergent theme: I was a mess waiting for my lung transplant. I was worried and scared and anxious;
78. Super-ordinate theme 2.f Psychological impact of CF (RD) – vulnerability versus control/ 4. CF (RD) positive aspects and meaning and purpose in life/ 5. CF (RD) and sense of self/Identity – Emergent theme: While waiting for a lung transplant I was starting to come to terms with my CF. I made a blog about my life;
79. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns - Emergent theme: Suddenly I had a whole community of friends;
80. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns - Emergent theme: I lost many friends;

81. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics/ 2.f Psychological impact of CF (RD) – vulnerability versus control – Emergent theme: When someone passes away from CF you're very depressed and anxious and it causes you to take stock;
82. Super-ordinate theme 2.e Psychological Impact of CF (RD) - isolation from others with CF – Emergent theme: Others with CF feel like family due to common struggles;
83. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns – Emergent theme: You think you'd be desensitized but every death took a toll on me;
84. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns – Emergent theme: Grappling with existential death anxiety;
85. Super-ordinate theme 2.d Psychological Impact of CF (RD) - transplant experience and existential concerns/ 2.f Psychological impact of CF (RD) – vulnerability versus control – Emergent theme: Looking for hints and clues. What did the ones who died from lung transplants do wrong;
86. Super-ordinate theme 2.b Psychological Impact of CF (RD) - emotional characteristics - Emergent theme: Psychological impact of waiting for a transplant- You start concocting all these paranoid theories;
87. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Hear me out and then be frank and reflect back the reality of what's actually happening;
88. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: It could help you to get past your fears and theories and see the reality;
89. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: It is helpful to give me scientific explanations about what's happening in my brain. I'm reassured by science;
90. Super-ordinate theme 3. CF (RD) as a non-visible illness/disability- Emergent theme: It's better now to disclose, to put your cards on the table;
91. Super-ordinate theme 2.a Psychological Impact of CF (RD) – Stigma/ 3. CF (RD) as a non-visible illness/disability- Emergent theme: It's not such a stigmatized thing anymore;

92. Super-ordinate theme 1.f Experience living with CF day-to-day-Significant cognitive impact – Emergent theme: We have to think in terms of time management and possible scenarios;
93. Super-ordinate theme 1.f Experience living with CF day-to-day-Significant cognitive impact – Emergent theme: Hyper planning and controlling over our space;
94. Super-ordinate theme 1.f Experience living with CF day-to-day-Significant cognitive impact – Emergent theme: Having to maintain vigilance in public places (think worse case scenarios/risk management/hyper-planners);
95. Super-ordinate theme 1.g Experience living with CF day-to-day- Existential responsibility - Emergent theme: You are the determinant of how well your lungs do;
96. Super-ordinate theme 2.f Psychological Impact of CF- vulnerability versus control - Emergent theme: You are your fiercest advocate and the master of your destiny;
97. Super-ordinate theme 3. CF as a non-visible illness/disability - Emergent theme: Having to fight to get my CF meds. You don't look sick;
98. Super-ordinate theme 3. CF as a non-visible illness/disability - Emergent theme: They don't believe me. You don't look sick;
99. Super-ordinate theme 2.c Psychological Impact of CF- the role of others/ 3. CF as a non-visible illness/disability – Emergent theme: The trauma of having to justify my illness;
100. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: CF has taught me the importance of compassion and empathy;
101. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: CF has made me cognisant of people's need to be heard, seen, supported;
102. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: CF has fueled my fire to go forward and defy ceilings;
103. Super-ordinate theme 1.a Experience living with CF day-to-day- symptoms & treatments/ 2.b Psychological Impact of CF-emotional characteristics/ 4. CF positive aspects and meaning and purpose in life – Emergent theme: We mature very quickly;
104. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: As much as I've been through what gave me back my meaning was my nephew, the joy of being present for his life;

105. Super-ordinate theme 4. CF positive aspects and meaning and purpose in life - Emergent theme: We don't live in a Fantasyland but there is still joy in moments;
106. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: I went from being angry about my disease and my future prospects to gain an expanded perspective as to how my disease informs my life. A transformational experience;
107. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments – Emergent theme: Integrating new treatments-remembering and finding the Mental Space;
108. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments – Emergent theme: adding new treatments- feels worse mentally- am I getting worse?;
109. Super-ordinate theme 1.a Experience living with CF(RD) day-to -day - symptoms & treatments – Emergent theme: Treatments – being tired, using more physical and mental energy then people without CF;
110. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: Worrying about how your family is feeling and the medications;
111. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: I think about how family thinks and feels before my own thoughts and feelings;
112. Super-ordinate theme 1.b Experience living with CF(RD) day-to-day- interpersonal relationships – Emergent theme: I kept my problems with CF, school to myself so as not to worry my family;
113. Super-ordinate theme 2.b Psychological Impact of CF(RD)-emotional characteristics - Emergent theme: Mix of education and CF contributed to burnout;
114. Super-ordinate theme 2.a Psychological Impact of CF(RD)-stigma – Emergent theme: Pushing the CF side back led to burnout;
115. Super-ordinate theme 1.c Experience living with CF(RD) day-to-day –impact on career/education/life path – Emergent theme: I was trying to be as normal as possible. Passing;

116. Super-ordinate theme 1.c Experience living with CF(RD) day-to-day –impact on career/education/life path - Emergent theme: I have CF but I have the same life expectations as everyone else to follow the normal life path;
117. Super-ordinate theme 1.h Experience living with CF (RD) day-to-day- CF and the impact of COVID – Emergent theme: COVID gave me time to breath/gave me a break- from expectations;
118. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life – Emergent theme: It's made me care less about the unimportant things (for example, drama in relationships) CF has given me perspective;
119. Super-ordinate theme 4. CF (RD) positive aspects and meaning and purpose in life – Emergent theme: CF has given me perspective-life is short therefore I want to focus on things I want to do;
120. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: Therapy has made me more comfortable talking about myself;
121. Super-ordinate theme 7.a Counselling and psychotherapy-helpful experiences – Emergent theme: Therapy has helped me to have more insight into my psychological processes and how to cope;
122. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Therapist attitudes that are important for me to talk openly - supportive and non-judgemental;
123. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Therapist attitudes that are important for me to talk openly - supportive and non-judgemental. Non-verbal too;
124. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Be well educated, encourage self-reflection, active listening, reflecting, some transparency so that we're both human/less hierarchical;
125. Super-ordinate theme 2.c Psychological Impact of CF- the role of others – Emergent theme: An internalized fear of abandonment;

126. Super-ordinate theme 1.b Experience living with CF day-to-day- interpersonal relationships/ 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: We don't want to burden people if we start to decline. Sticking with us means a lot;
127. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health -Emergent theme: Understand that CF is emotionally heavy. Once you earn our trust, we're in it for the long haul;
128. Super-ordinate theme 2.f Psychological Impact of CF(RD)- vulnerability versus control – Emergent theme: It's really difficult when you're at the bottom of it;
129. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: I don't need your false empathy;
130. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Understanding CF from a variety of standpoints;
131. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: As much exposure to the various spectrums of our disease would be an asset;
132. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Sit in at clinic appointments to get a sense of what questions we are asked regularly;
133. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Knowledge of the CF experience including clinic and PFTs, means a lot;
134. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: It's important to have exposure to patients on lung transplant list, to pulmonary function tests, join in CF Canada events to meet families;
135. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Knowing some medication names. Knowledge of CF in all its aspects;

136. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Base level understanding about medications/treatment protocols;
137. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Have an understanding about applications for medication/very stressful process for patients;
138. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Understand your patient's specific treatment regime/can help with context. How can we mitigate, how can we help you from a mental health standpoint;
139. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health -Emergent theme: Understand that CF is emotionally heavy. Once you earn our trust, we're in it for the long haul;
140. Super-ordinate theme 2. b Psychological Impact of CF (RD)- emotional characteristics/ 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Recognize that all of us living with chronic illness need mental health help/therapy: I had this dark thing inside of me;
141. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Understand that physical health does not necessarily reflect mental health and vice versa;
142. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Each CF patient has different experiences, different needs and are at different stages. Focus on whatever aspect of their life they need;
143. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Don't put me in a box. My mental health may be impacted by environmental factors not just my CF;
144. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Knowledge of anxiety and depression as well as techniques to help patient in the moment and techniques to teach patient healthy coping mechanisms;

145. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Helpful and important elements - intro meditation, writing down and referencing notes, recommending materials, where are we now and where do we go from here/goal setting;
146. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Read the room. We don't need you to cheer us up. We need you to get us moving;
147. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Respect boundaries (know where you can push and where you cannot). Be transparent. Have a dialogue;
148. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills -Emergent theme: Therapists need to have a balance of the light and the dark;
149. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills - Emergent theme: Integrating mental health at CF clinic appointments: telling other people's stories brings more of an all-encompassing aspect to our CF experience (medications, emotions, relationships). Using stories and narratives;
150. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: Have some sort of existential discussion on what CF means/the meaning of life as CF touches on death and mortality, where appropriate;
151. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills – Emergent theme: It would be very important to understand that CFers live with a lot of fear and uncertainty about the future;
152. Super-ordinate theme 6.a Observations and recommendations for CF counsellors/ psychotherapists-attitude, knowledge, and skills - Emergent theme: Understand the issues we are up against (help us to work through emotions re fertility, contemplating whether or not to be mothers);

153. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Having support in clinic from a mental and emotional side would help with the transition to adult clinic;
154. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills/ 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: More of a presence from a younger age. Normalization of the impact of CF on mental health. Also, for caregivers;
155. Super-ordinate theme 6.a Observations and recommendations for CF (RD) counsellors/ psychotherapists-attitude, knowledge, and skills/ 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Pop your head in at appointments. How's it going? I see you were sick here. Did that impact anything;
156. Super-ordinate theme 6.b Observations and recommendations for CF doctors, nurses and all allied health-integrating mental health – Emergent theme: Non-judgement. Look at underlying causes to non-compliance. Maybe there are some mental health issues behind it.

Appendix A

Participant Informed Consent Form

PARTICIPANT INFORMED CONSENT FORM

Title of study: A Patient- Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (CF).

OHSN-REB number: 2011046-01H

Principal Investigator: Dr. Smita Pakhale, (613) 737-8899

Investigator: Randy Leibovitch, MSW, RSW, M Ed Counselling, PhD (candidate) Counselling and Spirituality. Phone: (613)-737-8899

Thesis Supervisors:

Judith Malette, Ph. D., C. Psych.
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Full Professor Saint-Paul University
Faculty of Human Sciences and Philosophy

Martin Rovers Ph. D., C. Psych.
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Professor Saint-Paul University
Faculty of Human Sciences and Philosophy

Funding Agency: The Society for Pastoral Care and Counselling Research Grant. Saint Paul University.

Introduction

You are being invited to participate in a research study. You are invited to participate in this study because you have been diagnosed with cystic fibrosis (CF). This consent form provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

Please take your time in making your decision. You may find it helpful to discuss it with your friends and family.

Taking part in this study is voluntary. You have the option to not participate at all or you may choose to leave the study at any time. Whatever you choose, it will not affect the usual medical care, education or other services to which you are entitled or are presently receiving outside the study.

Due to the aim of this study, those with previous experience in counselling and psychotherapy may be preferred.

Is there a conflict of interest?

There are no conflicts of interest to declare related to this study.

The investigator for this study, PhD candidate Randy Leibovitch, is a member of The Ottawa Hospital Outpatient Adult Cystic Fibrosis Clinic interdisciplinary treatment team as a social worker/psychotherapist. To ensure research impartiality, she will participate in recruitment, facilitation of focus groups and semi-structured interviews where patients have been seen in therapy and have completed treatment and where they have not been seen in therapy as yet. Where Randy's ongoing patients wish to participate in this study, Dr. Smita Pakhale and potentially others will instead take part in their recruitment, focus group facilitation and semi-structured interviews.

Why is this study being done?

The aim of this study is to develop a patient- centred framework for counselling and psychotherapy with persons with a non-visible illness/disability: cystic fibrosis (CF), that counsellors and therapists can use to inform their practice. The methodology of this study is participatory action research (PAR): the idea is to work collaboratively together using your experience-based knowledge to develop a patient-centred framework for counselling and psychotherapy that is both meaningful and practical.

How many people will take part in this study?

It is anticipated that about 24 people will take part in this study, from research sites located in Ottawa, Ontario.

This study should take about six months to a year to complete, and the results should be known in about one to one and a half years.

What will happen during this study?

Your participation will begin with being part of a focus group with a semi-structured format. Focus groups will consist of approximately eight participants participating via Microsoft Teams video conferencing as per infection control protocols (Cystic Fibrosis Foundation Guidelines: 2013 update). Socio-demographic questionnaires and the PHQ-9 & GAD-7 will be completed and submitted to a researcher prior to the group (via email). In the focus group we will follow a Topic Guide, however, you will be considered a co-researcher in this study and your input is vital and welcome. Confidentiality within the group setting is a shared responsibility. As a member of this group you will be expected to not disclose the content of group discussions to anyone outside the group including any information that may personally identify another group member.

One to one semi-structured interviews, likely by telephone or Microsoft Teams, with some participants and a researcher will follow the focus group to further explore Topic Guide questions. The duration of the interview will vary from one individual to another, but the session may last between 45-90 minutes. Interviews and focus groups will be recorded. Data from the focus groups and semi-structured interviews will be coded into themes to develop a patient-centred framework for counselling and psychotherapy for persons with a non-visible illness/disability: cystic fibrosis. Your feedback on themes/the final framework will be requested to ensure that your values, ideas and experience are well represented.

How long will I be involved in this study?

The whole process will take approximately 1 to 2 hours for the focus group and between 45-90 minutes for the semi-structures interview, should you participate. We will also ask for your feedback on the emerging and final framework.

Can participants choose to leave the study?

You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. If you choose to withdraw from the study, you are encouraged to contact the research team.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the research team know. However, this would also mean that you withdraw from the study.

If you decide to leave the study, you can ask that the information that was collected about you not be used for the study.

What are the potential risks I may experience?

Given the sensitive nature of the subject matter at times, some feelings may come up during the course of focus groups and/or semi-structured interviews. You do not have to answer any questions that make you uncomfortable. Should you wish to debrief, a confidential opportunity will be provided by a researcher immediately after the focus group/interview or shortly thereafter.

What are the benefits of participating in this study?

The advantage of participating in this study is the unique opportunity to be a co-researcher in the development of a framework for counselling and psychotherapy with persons with a non-visible illness/disability: cystic fibrosis. This framework will be reflective of your knowledge and experience and may ultimately help others. You may gain a deep understanding of your needs in relation to your illness and the experience of counselling and psychotherapy. You may gain some understanding of the existential issues that you are up against and you may learn about how much you have in common with others.

How will participant information be kept confidential?

If you decide to participate in this study, the research team will only collect the information they need for this study. Data from the focus groups and semi-structured interviews will be coded into themes.

Records identifying you at this centre will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organization may look at your original (identifiable) medical records at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The Ottawa Health Science Network Research Ethics Board who oversees the ethical conduct of this study.

Information that is collected about you for the study (called study data) may also be sent to the organization listed above. Your name, address, email, or other information that may directly identify you will not be used. The records received by this organization may contain your Participant code, pseudo-initials, sex, and partial date of birth (month and year).

Communication via e-mail is not absolutely secure. We do not recommend that you communicate sensitive personal information via e-mail.

During the discussions, participants will be encouraged to refrain from using names. If names or other identifying information is shared during the discussion, it will not be included in the written records.

The video/audio recordings will be stored in a secure location and viewed only by members of the research team. The recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will form the basis of a patient-centred framework for counselling and psychotherapy with persons with a non-visible illness/disability: cystic fibrosis. The results of this study may be published/presented to the scientific community at meetings and in journals.

Your de-identified data from this study may be used for other research purposes. If your study data is shared with other researchers, information that links your study data directly to you will not be shared.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated.

What is the cost to participants?

Participation in this study will not involve any additional costs to you or your private health care insurance.

Are study participants paid to be in this study?

If you decide to participate in this study, you will receive $30 as appreciation for

voluntarily choosing to participate in this research project.

Whom do participants contact for questions?

If you have questions about taking part in this study, you can talk to the investigator, Randy Leibovitch, at: (613)-737-8899. You can talk to your study doctor, or the doctor who oversees the study at this institution. That person is:

Dr. Smita Pakhale	(613)-737-8899
Principal Investigator Name	Telephone

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact The Ottawa Health Science Network Research Ethics Board, Chairperson at (613)-798-5555 extension 16719.

For information about your rights as a participant, you may also contact the Office of Research and Ethics, Saint Paul University, 223 Main Street, Ottawa, Ontario K1S 1C4. Phone: (613)-236-1393.

Study Title: A Patient- Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (CF).

Signatures:

- All my questions have been answered,
- I understand the information within this informed consent form,
- I allow access to medical records and related personal health information as explained in this consent form,
- I do not give up any of my legal rights by signing this consent form,

Signature of Participant/ Substitute Decision-Maker	Printed Name	Date

Signature of Person Conducting the Consent Discussion	Printed Name and Role	Date

Study Title: A Patient- Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis (CF).

Participant Assistance

Complete the following declaration only if the participant is <u>unable to read</u>:

☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to the participant, and any questions have been answered.

Signature of Impartial Witness	Printed Name	Date

Relationship to Participant

Complete the following declaration only if the participant <u>has limited proficiency in the language in which the consent form is written and interpretation was provided</u> as follows:

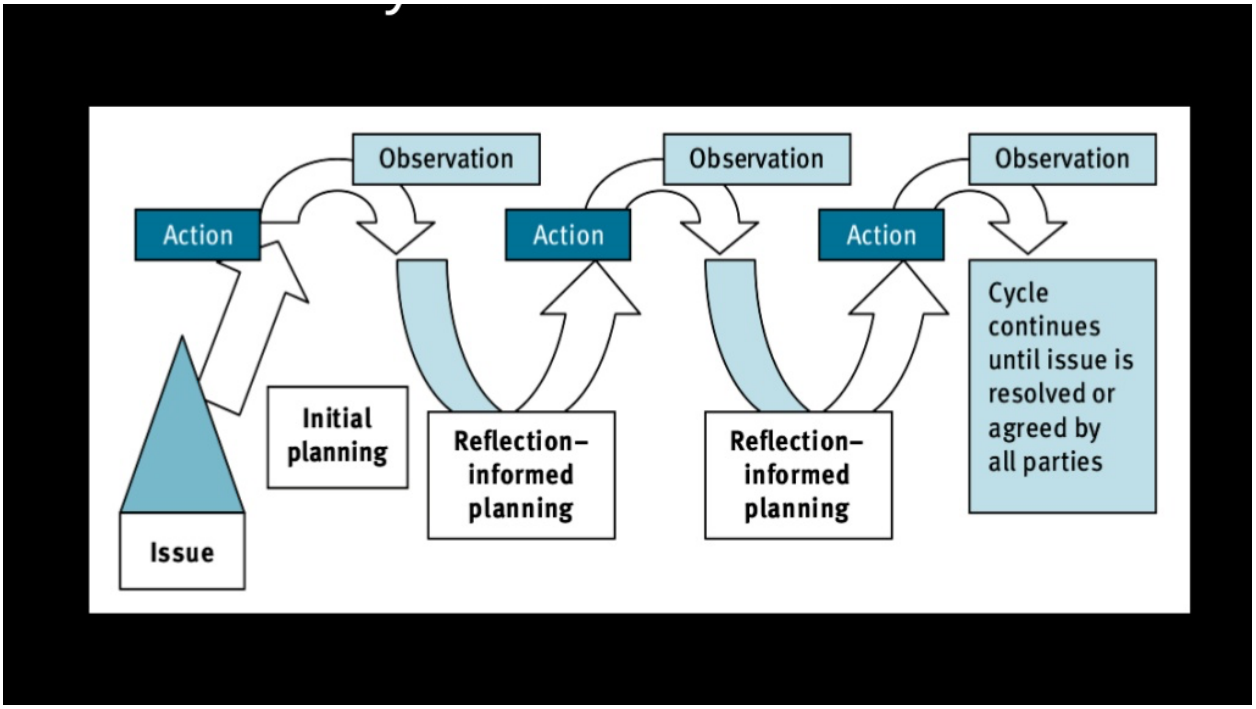
☐ The person signing below acted as an interpreter, and attests that this study as set out in the consent form is accurately sight translated and/or interpreted, and that interpretation was provided on questions, responses and in additional discussion arising from this process.

Signature of Interpreter	Printed Name _____	Date

Version date: April 24, 2020

Appendix B

Multiple Sequences of PAR



Appendix C

Topic Guide (Revised)

Your answers to the following questions will be developed into themes and then a framework for counselling and psychotherapy with persons with CF. We're going to ask you a series of questions:

Problem identification/needs analysis:

1. Can you speak about what it's like to live with CF day to day– a few aspects of your experience that you would like to share;

2. Can you speak about what problems come up living with CF? **For example, some people have issues in their family or when reaching out to health care professionals. Does this resonate with everybody? Some people struggle with their mental health or with motivation to stick with treatments. Does this fit for some? Please say more…please give examples;*

3. How has the fact that CF is a non-visible disability impacted you? Please give examples;

4. How has your illness impacted your sense of meaning and purpose in life? Are there positive aspects to living with CF? Please say more and give examples;

Questions regarding necessary counsellor/therapist attitudes, knowledge, skills and what would constitute a patient-centred framework for counselling and psychotherapy with persons with CF:

5. What attitudes are important in your counsellor/therapist for you to feel like you can talk openly with them? **For example, is it important that they are non-judgmental, open, accepting, present and why? Anything else?;*

6. What knowledge and skills are important for your counsellor/therapist to have in order to work with you most effectively? **For example, is it important that they understand the specifics of your illness and the day to day aspects of living with CF and why? Is it important that they understand the impact of chronic illness on mental health and why? Is it important that they know different approaches to therapy, for example, Mindfulness practices and why? Should they be trauma and LGBTQ+ informed? Please say more/elaborate. Please give examples from your experience;*

7. If you have reached out to a counsellor/therapist within or outside of the hospital system what experiences stand out for you that you would like to share:

a) Please give examples of any helpful experiences;
b) Please give examples of any unhelpful experiences:

8. Imagine that you have gone to a counsellor/therapist and it's been the best experience imaginable. What did that look like for you? What were the sparkling moments/ the important elements that made that encounter great?

9. After hearing everyone's answers as well as your own, what recommendations would you have for therapists working with persons with CF?

Reflection questions on the methodology used in this research:

10. In this study our method of investigation is participatory action research (PAR), which emphasizes collaborative involvement and action (achieving a result). Focus groups and semi-structured interviews are part of participatory action research. Would you say that by using PAR we are capturing what we are after in this study- developing a patient-centred framework for counselling with persons with CF? What other ideas might you have for this study? Please share;

11. What are your thoughts about sharing our results/patient-centred framework for counselling, with other CF patients at the Ottawa clinic and requesting feedback before we finalize it?

12. How should we disseminate the framework to have the greatest impact on counsellors/therapists and patients? For example, should we develop a pamphlet (for example, counselor/therapist dos and don'ts) and/or write an article to submit to a journal? Please share your ideas.

What have we missed? Anything else to add?

Thank you!!!!

*please note that the italicized sections on questions 2, 5, and 6 are meant as prompts if the discussion slows or gets off track.

Appendix D

Recruitment Letters

Initial Recruitment Letter:

Subject: Help us to help you-ground-breaking research!

(OHSN REB # 2011046-01H; Saint Paul University REB #1360.1/20)

Hi Everyone,

Please find attached an invitation (and consent form) to participate in a research study. We are interested in your thoughts regarding what is important to you in counselling and psychotherapy and how therapists could best address your needs. Together, we'll develop a patient-centred framework for counselling and psychotherapy which may positively impact you and others. Taking part in this study is completely voluntary.

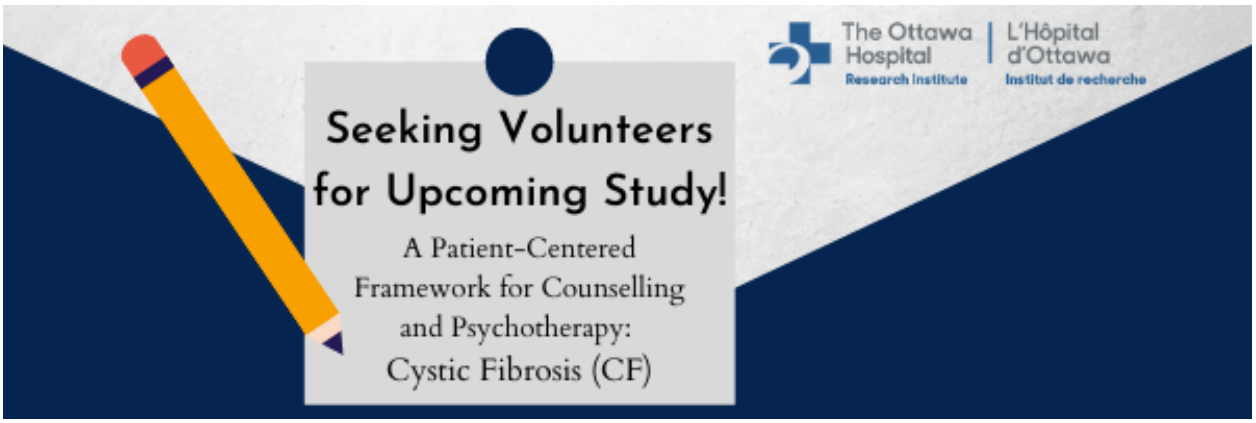
Please reply to this email if you are interested in participating. We will then connect you with a member of our research team regarding next steps.

Thank you!

Ena on behalf of the research team

Revised Recruitment Letter:

Subject: Help us to help you-ground-breaking research!
(OHSN REB # 2011046-01H; Saint Paul University REB #1360.1/20)



Hi Everyone,

Thank you to those who have already volunteered! We are still looking for CF patients who would want to join our study.

What is the purpose of the study?
To develop a CF patient-centred framework for counselling and psychotherapy.

Format
This study will connect CF patients virtually, to share your experiences, brainstorm ideas and give feedback on how the Ottawa Hospital can best support CF patients and their mental health.

Your collaboration will help us to better equip our staff, so that whenever you are in need of support or guidance; our CF care is responsive to your needs.

Time Commitment
Your participation in the study includes 1 focus group meeting (about 1-2 hours), possibly followed by 1 one on one interview (about 1-2 hours).

Please reply to this email if you are interested in participating. We will then connect you with a member of our research team regarding next steps.

Thank you!
Ena on behalf of the research team

Final Recruitment Letter:

Subject: Help us to help you-ground-breaking research!
(OHSN REB # 2011046-01H; Saint Paul University REB #1360.1/20)

Hi Everyone,
You are being invited to participate in the final portion of a research study.

What is the purpose of the study?
We have co-created a patient- centred framework for counselling and psychotherapy for persons with a non-visible illness/disability: cystic fibrosis (CF). The framework was developed by and for persons with CF at our Ottawa Hospital Outpatient Adult Cystic Fibrosis Clinic and is written in their own words. The purpose of the framework is to better equip our CF interdisciplinary team, so that whenever you are in need of support or guidance; your CF mental health care is responsive to your needs.

Your participation
We are asking for your collaboration to ensure that the framework is strong and meaningful to most. Should you choose to participate please read through the framework (attached) and send your feedback/comments directly to Ena or to: rleibovitch@toh.ca (our social worker and mental health counsellor).

Voluntary participation and Consent
Taking part in this study is voluntary. Whether you participate or not will not affect the usual medical care, education, or other services to which you are entitled or are presently receiving outside the study. Your feedback/comments will indicate your consent to participate in the final portion of the study.

Confidentiality
Your feedback/comments will be considered and incorporated where appropriate into the framework. All identifying information (names etc.) will not be included. If the results of this study are presented or published, your identity will remain confidential.
Thank you!

Ena on behalf of the research team

Appendix E

Focus Group Facilitator Cheat Sheet (Revised) and Focus Group Participant Cheat Sheet

Focus Group Facilitator Cheat Sheet

What is a focus group? A focus group is a small group discussion guided by a facilitator or facilitators to generate discussion and learn about participants' opinions on a designated topic. While a focus group is a supportive environment, it differs from a support group in that it has a goal/tangible result.

Goal of the facilitator: Lead and carry the discussion questions on the research topic while remaining in a neutral manner.

Why are focus groups useful?

- They provide a wide representation of diverse opinions and ideas;
- They provide information from people with experience-based knowledge who can offer insight into the actual situation, conditions, goal.

Three golden rules of ethical research:

- **Respect for persons** (recognition of each person's dignity, autonomy, uniqueness and freedom);
- **Concern for welfare** (importance of confidentiality, and minimizing risks);
- **Justice** (ensuring equal opportunity and that the larger goal meets participants' needs).

Steps to conduct a focus group:

1. Briefly introduce yourself as co-facilitator….one thing you might want to know about me; and/or name one hidden talent;

2. Thank people for coming. Have everyone introduce themselves. Icebreaking exercise could be any of these: share one reason why you're here; and/or one thing you might want to know about me; and/or name one hidden talent;

3. Explain that the focus group will be 1.5-2 hours in duration;

4. Review the purpose/goal of the focus group: "we are here to tap into your experience-based knowledge to develop a framework for counselling with persons with CF that would work well for you and others";

5. Briefly describe your roles as co-facilitators, for example, one person will ask the questions while another is focused on ensuring everyone has a voice/chance to be heard. You might switch roles (decide this beforehand together);

6. Ask people how they want to indicate that they have something to say (hand up etc.…);

7. Ask people if they will need a break and when would be appropriate, for example, after each section? “Is there someone who would want to manage the time per question, or should we just wing it and see how it goes?”

8. Emphasize that we want this to be a safe space for everyone. Tools in place to make this a safe space include: pausing the conversation and checking in with everyone now and again -how is this going so far?; taking breaks; having Randy on call during the focus group should anyone be triggered/upset; and/or being able to talk to Randy and/or one of the co-facilitators after the focus group, if they need to. Ask people what else they would need to make this a safe space? Suggestions?

9. Go over ground rules:

    - This is a focus group. A group with a purpose. Our aim is to hear your experience and opinions and begin to translate these into a patient-centred framework for counselling for persons with CF. The group may be 1-2 hours long;
    - It is important to hear from everyone;
    - Please let’s have one person speak at a time. No side conversations. This is also important as we are recording;
    - Please be respectful of others’ opinions. There are no right or wrong answers;
    - It is important to stay the entire time if possible. However, if a topic is triggering or uncomfortable, you don’t have to answer, and you have the option of leaving the conversation. You can consult with the principle researcher, Randy, during the group or after if you need to debrief. You can also consult with one of us/the co-facilitators after group;
    - Please turn off phones;
    - All information must remain confidential. Help to protect other’s privacy by not discussing identifying details (names, gender, content) outside the group please.

10. Ask one question at a time on the Topic Guide. The italicized sections on questions 2, 5, and 6 are meant as prompts if the discussion slows or gets off track;

11. End discussion by summarizing the main points, main ideas, and ask if anyone has final thoughts to share;

12. Thank the group for participating! Maybe have a wind down exercise of your choice.

DO’s	**DONT’s**
√ Use neutral phrases such as *“Thank you for your response, that is helpful.”*	× Use phrases such as “*You really think that?” “ I can’t believe it”*
√ Create a safe, non-threatening environment	× Interrupt the participant while speaking to share your opinion
√ Listen carefully to participants and be patient. Only after prolonged silences	× Make assumptions

attempts to paraphrase a question may be made √ Use probes when necessary such as *"Please tell me more, could you explain what you mean by that, could you please give an example of that"* √ Check in with the participants with how they're doing √ Keep track of time √ Address questions to individuals who are reluctant to talk √ Give nonverbal cues (look in another direction, or stop taking notes when an individual talks for an extended period of time) √ Pay attention to your personal body language, show that you're actively listening (e.g. nodding, affirming that you have heard them) √ End up discussion with a summary of it and ask participants to express any ideas that have been omitted but are important to them.	× Ask leading question such as, "*Don't you think….."* × Ask new questions that are not on the script × Share personal stories on the topic × Make confused faces when someone is talking × Encourage side conversations × Read the script word for word × Favour one participant over others × Finish people's sentences × Use technical terms × Take it personally

Difficult Situations:

What do I do if someone is dominating the conversation?

- It is important to notice when this is happening in order to give others the opportunity to speak. Respectfully acknowledge their contribution and thank them by saying *"I really appreciate your comments."* Then make eye contact with someone else and say *" I am very interested in hearing about how other people are feeling about this issue."* or *" It's very interesting to get a variety of perspectives, and I would like to hear from other people as well."*
- *If things get complicated you can bring up the 2,2,2 rule. You can say, "has anyone heard of the 2, 2, 2 rule? Person speaks for 2 minutes, waits for 2 more people to talk, and holds for another 2 minutes before talking again."*
- *Can also ask again if anyone wants to be a timekeeper and, if so, what would be a reasonable time for each question.*

What do I do if women and men are participating at different levels? I.e. men are speaking more than women or vice versa?

- Use similar strategies as mentioned above, thank the participant and mention *"It would be interesting to hear from some of the women in the group."*

What do I do if no one responds to the question?

- If no one responds, it is okay to just wait it out for a bit to give people time to think.
- In this situation it is helpful to understand why people aren't responding:

- Did you ask a question that was difficult for the participants to understand?
  - Try asking the question in a different way
- Do you think you might have asked a politically sensitive question and individuals are triggered by it?
  - Skip the question and try coming back to the question later
  - Use probes or rephrase the question
- Are people getting tired of talking?
  - Maybe it is time for a short break
  - Probe with *"Is there anything else that you would like to share, if not we can move on to our next question."*
- Are people feeling uncomfortable about talking?
  - Often this occurs at the beginning of the focus group
  - Maybe try asking an easier question first

What do I do if the group begins to talk about topics that are not relevant to the research?

- This often happens when the discussion takes a turn, away from the topics of the focus group. When this happens, pause and say, *"Thank you for that interesting idea, perhaps we can discuss it in a separate session. Right now for time constraints, I would like to move onto the next question if that's okay."*
- Use this as an opportunity to probe the group by saying, *"Is there anything else someone would like to share on the question."*
- *Bring the group back to the purpose of the study, for example, "So, how do you think that would apply to a counselling framework for CF?"*

What do I do if people are having side conservations?

- Side conversations can disrupt the focus group by making participants feel uncomfortable or hard for people to hear what others are saying.
- Best ways to handle this is to address it before the focus groups begin as one of the ground rules. If side conversations occur, kindly remind participants of the ground rules.

What if the participant provides information or answers a question that I have not gotten to yet?

- At times participants may skip topics or move ahead of the facilitators guide. This is where you will want to use probes to get detailed information about the question. Do not interrupt them, let them finish first before asking the probing question.
- Still re-ask the later question that was already answered by acknowledging that relevant information was already shared.
- Make sure all questions are discussed as completely as possible.

What do I do if I ask a question and the participant says they do not feel comfortable answering it?

- That is totally okay if they do not feel like answering a question. Make this clear in the beginning in the ground rules.
- Say, *"Thank you and I appreciate your honestly."* Then ask if it's okay to move onto the next question

What do I do if people begin leaving?

- It is important to keep people fully engaged in the discussion for the entire focus group.
- Tell people in the beginning how long the focus group will be and emphasize that it is important to stay the entire time if possible.
- If a topic is triggering or uncomfortable, participants do have the option of leaving the conversation. They can consult with the principle researcher, Randy, if they need to debrief.

What if the topic starts to bring tension between participants?

- In this case, remain neutral by saying "We are hearing a lot of passionate opinions right now. Let's remember to keep it focused on the issue and not on each other."
- Recognize there is a disagreement but bring it back to the research question by saying, "There seems to be a disagreement here. I would like to remind everyone to keep focused on the research question."
- Remind everyone of the ground rules, for example: Please be respectful of others' opinions. There are no right or wrong answers;

Focus Group Participant Cheat Sheet

What is a focus group? A focus group is a small group discussion guided by a facilitator or facilitators to generate discussion and learn about participants' opinions on a designated topic. While a focus group is a supportive environment, it differs from a support group in that it has a goal/tangible result.

Why are focus groups useful?

- They provide a wide representation of diverse opinions and ideas;
- They provide information from people with experience-based knowledge who can offer insight into the actual situation, conditions, goal.

Three golden rules of ethical research:

- **Respect for persons** (recognition of each person's dignity, autonomy, uniqueness and freedom);
- **Concern for welfare** (importance of confidentiality, and minimizing risks);
- **Justice** (ensuring equal opportunity and that the larger goal meets participants' needs).

Focus group ground rules:

- This is a focus group. A group with a purpose. Our aim is to hear your experience and opinions and begin to translate these into a patient-centred framework for counselling for persons with CF. The group may be 1-2 hours long;
- It is important to hear from everyone;
- Please let's have one person speak at a time. No side conversations. This is also important as we are recording;
- Please be respectful of others' opinions. There are no right or wrong answers;
- It is important to stay the entire time if possible. However, if a topic is triggering or uncomfortable, you don't have to answer, and you have the option of leaving the conversation. You can consult with the principle researcher, Randy, during the group or after if you need to debrief. You can also consult with one of us/the co-facilitators after group;
- Please turn off phones;
- All information must remain confidential. Help to protect other's privacy by not discussing identifying details (names, gender, content) outside the group please.

Appendix F

Socio-demographic Questionnaire (Revised)

<u>Socio-demographic Questionnaire</u>:

1. **Gender identity: _____**
2. **Age: _____**
3. **Age at CF diagnosis: _____**
4. **Language: _____English _____French ____Other (please specify):**
   _____
5. **Residence:**

   City or Town: _____ Province: _____ Country: _____
6. **Living status:**

   _____ Living independently
   _____ Living with parents/family
   _____ Living with spouse/partner
   _____ Living with roommate (s)
   _____ Other (please specify):
   _____
7. **Relationship status:**

   _____ Single
   _____ Partnered/Common Law/Married
   _____ Separated/Divorced
   _____ Widowed
   _____ Other (please specify):
   _____
   _____

8. Employment status (you may tick off more than one item):

_____ Full-time
_____ Part-time
_____ Student
_____ ODSP or another provincial equivalent
_____ Unemployed/Retired
_____ Other (please specify):

---

9. Education:

_____ Elementary/Primary School
_____ High School/Secondary School
_____ College Diploma
_____ University: undergraduate
_____ University: graduate
_____ Other (please specify):

---

10. Are you a person with (you may tick off more than one item)?

_____Cystic Fibrosis between the age of 18-30
_____Cystic Fibrosis Related Diabetes (CFRD)
_____Cystic Fibrosis 39 +
_____Other (please specify):

---

11. Do you identify as someone with a non-visible illness/disability? ____ Yes ___ No. Please elaborate:

---

12. Do you have previous experience as a client/patient in counselling and psychotherapy? ____ Yes ____No. Please elaborate:

Thank you for your participation!

Appendix G

PHQ-9 & GAD-7

PATIENT HEALTH QUESTIONNAIRE- 9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING _____+_____+_____+ _____

=Total Score: _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

GAD-7
(The Generalized Anxiety Disorder Assessment)

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Add the score for each column	+	+	+	
Total Score *(add your column scores)* =				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all _____
Somewhat difficult _____
Very difficult _____
Extremely difficult _____

.

PHQ-9 and GAD-7 Scores & Treatment Actions

PHQ-9 score	**Depression severity**	**Proposed treatment actions**
0–4	None–minimal	None
5–**9**	Mild	Watchful waiting; repeat **PHQ-9** at follow-up
10–14	Moderate	Therapeutic **treatment** and follow-up/antidepressants
15–19	Moderate–severe	Antidepressants and therapeutic **treatment**

GAD-7 score	**Anxiety severity**	**Proposed treatment actions**
0-4	None-minimal	None
5-9	Mild	Monitor
10*-14	Moderate	Possible clinically significant condition
>15	Severe	Active treatment probably warranted

(Kroenke & Spitzer, 2002; Spitzer et al., 2006).

Appendix H

A Patient-Centred Framework for Counselling and Psychotherapy with Persons with a Non-Visible Illness/Disability: Cystic Fibrosis

Preamble

Every patient and member of the CF interdisciplinary team have the right to be treated with courtesy and respect and in a way that fully recognizes their inherent dignity, worth and individuality, regardless of their race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability7

Counsellor Attitude:

- It is important to have full trust in you. To build trust and a therapeutic alliance:
- Please be empathetic, genuine, supportive, sincere, kind and easy to talk to. Establish a professional but friendly connection. A sense of humour, where appropriate, is an asset;
- Be non-hierarchical (walk beside me). Be open-minded and non-judgmental (even non-verbally);
- Practice active listening, validate my feelings, recall accurate details of my story;
- Establish trust by asking me what I need to feel supported;
- Be transparent and practice skillful self-disclosure. For example, bringing in your own life experiences when I'm feeling insecure makes the session more personal for me. Please don't assume that you know how I am feeling or share at moments when we're trying to explain, when it's better to listen and understand;
- Be tactful, gentle, and respectful with time keeping and transitions. For example, you might say, "I don't want to interrupt your flow, but the session is ending;"
- Be supportive of me in clinic, an ally when I am feeling judged for not being perfect with my treatment protocols;
- Look at me not just as a disease but as a human being. Understand that there's an overarching theme of CF, but also wanting to feel normal. There is more to me than CF: remind me that CF is not who I am;
- Have a balance between the light and the dark. Have a thick skin because sometimes we are a dark disease, and we go to dark places, and I might lash out at you because I'm in pain. It's not a personal attack;
- It is important to be able to see you within a reasonable time. Be accessible and ensure that there is a structure for follow up, that I don't fall through the cracks;
- Respect boundaries. Let us know when you are available and be there if we need you to the extent that we need you;

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7 The preamble has been adapted from the Ontario Residents' Bill of Rights, embedded in the Fixing Long-Term Care Act (FLTCA), 2021 and accompanying Regulations (O.Reg. 246/22) www.ontarc.com

- I need you to not overstep but also to know that you won't leave. I don't want to be abandoned. We need a counsellor who is comfortable to stand beside us when CF gets tough;
- Once you earn our trust, we are in it for the long haul.

Counsellor Knowledge:

- Please understand that CF and mental health go hand in hand. We are dealing with a chronic and possibly life limiting illness that affects our quality-of-life day to day. If we are not feeling well emotionally this could affect our motivation for treatments and then our overall health might decline;
- Please have knowledge of anxiety and depression and trauma. Bad episodes of hemoptysis, difficult acute care experiences, transplants, losing others to CF and parenting a child with CF can cause trauma and trigger PTSD. Help us to develop healthy coping mechanisms and have knowledge of various techniques to help us to do so;
- Understand our specific treatment regime and how we can mitigate the treatment load from a mental health standpoint;
- Know more about CF than what Wikipedia tells you. I want somebody who's passionate about CF - or understands about mental health and chronic illness;
- Have knowledge that CF is a spectrum-it affects everybody differently and sometimes where you are on the spectrum changes day to day. Have background knowledge of CF from a variety of standpoints and real experience/exposure;
- Take our lead in terms of where we are on the spectrum. Be cognizant that we're knowledgeable as a patient group about what is affecting us. We're a different kind of sick - we're the experts on CF as we have been living with it our whole lives;
- Have a base level knowledge of our day-to-day routines and stressors, the struggles we go through, the medical and financial components that come with CF: for example, understand that CF is emotionally heavy, that we may experience loss when our health declines, the medications we are taking (interactions and the long-term effects), our treatment protocols, the stressful bureaucracy and paperwork/applications for medications;
- Sitting in on clinic appointments to get a sense of what we face and what questions we are asked regularly would be an asset as well as joining in CF Canada events to meet with families;
- Understand that physical health does not necessarily reflect mental health and vice versa. I can look relatively fine but be struggling from a mental health perspective;
- It's important for a counsellor who deals with the CF population to not take it at our word that we're fine because we're used to putting up a front to be strong for others. Be aware of the burden complex: I don't want to burden other people. I need to learn to ask for help;
- You need to have a keen understanding that carrying a lot of this can be very numbing emotionally;
- Appreciate that we are all persons first/we are so many other things -husbands, wives, partners, parents, students, and full or part time workers. Having to juggle all these roles with treatments/being sick sometimes/not feeling like we are good enough in any of these roles can mean that feeling mentally exhausted is often part of our day to day life;
- Don't put me in a box. Understand that my mental health may be impacted by environmental factors not just my CF. Recognize that, depending on where we are on the

spectrum of CF, we may have various levels of mental health concerns and require different levels of support. I don't want to be treated sicker than I am;

Counsellor Skills:

- As my counsellor/therapist know that every person with CF has different experiences, different needs and are at different stages. Please focus on whatever aspect of our life we need help with. I don't want to only focus on CF;
- When we're new to therapy, ask questions to get us thinking. Begin by focusing on topics that we are comfortable with to build rapport and trust. Also, normalize seeing a therapist and, if appropriate, give examples of what others with CF are up against that might resonate;
- Begin with a grounding exercise to help us to transition into sessions and hone this skill for when we need it (when overwhelmed and stressed). Mindfulness exercises at the beginning of sessions really make a difference;
- Ask what matters to me, what I'm bringing in today to talk about. Help break things down within the session to tangible components to work on. Help with short- and long-term goal setting. The goal of the therapy and the process must be established at the beginning to avoid confusion or expectations. Let's end the session on a positive note, and focus on what we can work on next session;
- Have a personalized approach (to meet my personality type, what coping mechanisms work for me and to get to know how I like to be nudged and supported). My ideal session: this is how my brain works, this is what I need and the counsellor remembering the micro details;
- Ask the right questions to help us to communicate/put our thoughts and feelings into words and be honest with ourselves, so that we can gain a deeper self-awareness (light bulb moments). I'm "fine" as a default: I need someone to pierce through that. Create a safe space for me to learn how to sit with my deep/hard emotions and know that I'm going to be okay. Where we have trouble finding the words to express our feelings, maybe have a visual chart that breaks down the different emotions;
- Challenge us. Teach me different skills and coping strategies. Point out patterns, touch back on some of the things discussed as a reminder, give concrete feedback about my progress, and help me to grow from each therapeutic experience. What makes a session sparkling is when I feel empowered/ I know I've made progress & carried over the skills that I've learned;
- Engage in a conversation/a dialogue with me: pushing on certain issues, letting others go- I don't want to spin around in my own problems. I want to leave with a bit more clarity;
- Hear me out and then be frank, sometimes it's helpful to provide factual science-based information to reassure me when I'm spinning out;
- I need boundaries to be an ongoing conversation: when to push and not push knowing that eventually the lines will need to move to delve into the touchy areas, the dark stuff. It's helpful to have a counsellor where you're forced to face those harder points that you were afraid of or weren't aware of -we have a lot of fear and anxiety about the future and have to face a lot of difficult issues;
- Help us to work through emotions regarding reproduction, fertility, and how our body functions. I go to a therapist to guide me, to be present with me when I'm sick and to talk

about the uncomfortable side of CF. Please do not force positivity but meet us where we are at no matter how uncomfortable, no matter how dark;
- It's okay to have some sort of existential discussion with me, where appropriate, on what CF means/the meaning of life as CF touches on death and mortality;
- In the social media era, getting in touch with others with CF (or parents of CFers) can give us a sense of belonging to a community and a purpose. It can also mean that we don't cultivate who we are without CF. This can lead to a real identity crisis as many of us now have access to modulators and can lead a more "normal" life. Please help us to navigate through this;
- Keep it grounded. I don't need a hero complex. We don't need false empathy or fake validation of our strengths. I need: that's a lot to carry, what do you need to do to self-care;
- Listen to my needs and where I'm at. Don't push your opinion on me about what I should do or how I should take care of myself-let that be a joint endeavor;
- Because lessons don't only happen in the therapy room, provide me with tangible resources to be able to practice, for example, book recommendations and relevant take aways/homework exercises. I need a strategy to practice something: I need that as something to hold onto;
- Sometimes we need a structured approach, an empathetic solution focused action plan, as opposed to just listening. For example, guide us and connect us to the right supports and resources for our situation. Be aware of services and reassure me that it's okay to use them;
- When we ask, or where it is necessary, communicate with our CF medical team regarding our mental health. It's important for our therapist to help interpret our intentions and feelings when we don't always have the voice to do it ourselves. Help advocate for our mental health and concerns, because mental health and physical health are very linked, but it does unfortunately happen that medical help doesn't always factor in our mental health or emotional perspective;
- If possible, provide not just talk therapy but look at creative options that resonate with me to deal with things.

A Note to our CF Clinic Team:
- Please normalize and integrate mental health by making it part of your check list. For example, if you see that I'm sick you can ask, "with everything going on how is your mental health?" If I have a mental health diagnosis, you can ask, how is this effecting your anxiety or depression or --------? Please wait to hear the answer;
- Even if I appear to be doing okay ask how I am coping, nonetheless. Open ended questions are best. For example, you can ask, "is there anything you would like to discuss today?" Please don't assume that if someone seems physically okay, they're mentally doing okay;
- Please take the knowledge and exposure learned from having treated so many as precedent to inform my case. Also understand that each CF patient is unique;
- Please understand that there may be underlying causes to my "non-compliance." Instead of judging or telling me what I should do, create a safe space, listen to my needs and where I'm at, ask questions, and give me time to respond. Walk beside me. Let's collaboratively come up with a plan that works over time;
- In terms of asking questions, please bring in a mental health lens to how questions are asked. This begins by letting me walk you through my thought process and circumstances and then meeting me there and collaboratively discussing treatment options. For example,

you can ask, “are there any side effects to your medications that impact your willingness to take them? If so, what would work moving forward?” A mental health lens allows for personalized care and reinforces patient ownership;

- The CF care team has pretty good cohesion and follow up. Please ensure that there is feedback/follow up even if the situation seems non-urgent. What I want to avoid is you not doing anything because I’m not sick enough. Please follow up/check in sooner, re-evaluate as my health evolves, and be transparent about where the process is at. Sometimes we just want to know that there has been a step toward something;
- It would be helpful if when a mistake is made, when something is missed, that this is acknowledged, and we talk about it openly. Otherwise, it feels like gaslighting with the event remembered as a trauma;
- Prepare us. Talk about the potential progression of CF, even lung transplant. This might help us to be more vigilant about our care, and engage in present and future planning;
- Please ensure that there is synergy between our CF clinic doctors, nurses and social work/mental health. Social work/mental health should be as integral to the health care team as our CFRD nurse. Refer us when we ask, when we’re having a hard time, when we’re about to have a transplant and when we transition to adult clinic;
- Ideally, the social work/mental health position should be full time and not shared with other clinics. Social work/mental health should provide a continuous program, ongoing support geared toward patient need rather than a set number of sessions. The therapy must be available as long as the patient needs it or have a plan to transition to another qualified professional. Where there is an intern assigned, please ensure that they have the experience, training and supervision to provide competent counselling/psychotherapy services;
- Where social work/mental health is involved, we should be given options, for example, individual or group therapy, virtual or in person sessions, sessions outside of clinic hours. Groups should be run by social work/mental health, and they should be structured. Groups might be helpful to find community and social connection;
- There should be some sort of “therapy onboarding” for both patients and social work/mental health, for example, a Cheat Sheet about the common issues we are dealing with/the BIG themes. This will be validating for patients and informative for all.

Patient Role:

- It is important that we as patients are engaged in counselling and that we contribute to the process for it to work;
- Although it could be difficult to express mental health problems and concerns our role is to speak up and be transparent. Our medical team and social work/mental health can’t help if they don’t know that something is wrong;
- We need to keep in mind that this is a collaborative process, with the goal of finding the best possible treatment plan. Our role is to express what we’re feeling and thinking, to ask questions and to voice when we feel discomfort;
- It is important to understand that our CF team may have limits to what they can do to help, that they can’t work miracles;
- Patients have a responsibility to consider our CF team, who also have everyday issues and struggles.

Appendix I

Columbia-Suicide Severity Rating Scale (C-SSRS)

COLUMBIA-SUICIDE SEVERITY RATING SCALE (C-SSRS)

Posner, Brent, Lucas, Gould, Stanley, Brown, Fisher, Zelazny, Burke, Oquendo, & Mann
© 2008 The Research Foundation for Mental Hygiene, Inc.

RISK ASSESSMENT

Instructions: Check all risk and protective factors that apply. To be completed following the patient interview, review of medical record(s) and/or consultation with family members and/or other professionals.

Past 3 Months	Suicidal and Self-Injurious Behavior	Lifetime	Clinical Status (Recent)
☐	Actual suicide attempt ☐ Lifetime	☐	☐ Hopelessness
☐	Interrupted attempt ☐ Lifetime	☐	☐ Major depressive episode
☐	Aborted or Self-Interrupted attempt ☐ Lifetime	☐	☐ Mixed affective episode (e.g. Bipolar)
☐	Other preparatory acts to kill self ☐ Lifetime	☐	☐ Command hallucinations to hurt self
☐	Self-injurious behavior ***without*** suicidal intent	☐	☐ Highly impulsive behavior
Suicidal Ideation Check Most Severe in Past Month			☐ Substance abuse or dependence
☐	Wish to be dead		☐ Agitation or severe anxiety
☐	Suicidal thoughts		☐ Perceived burden on family or others
☐	Suicidal thoughts with method (but without specific plan or intent to act)		☐ Chronic physical pain or other acute medical problem (HIV/AIDS, COPD, cancer, etc.)
☐	Suicidal intent (without specific plan)		☐ Homicidal ideation
☐	Suicidal intent with specific plan		☐ Aggressive behavior towards others
Activating Events (Recent)			☐ Method for suicide available (gun, pills, etc.)
☐	Recent loss(es) or other significant negative event(s) (legal, financial, relationship, etc.)		☐ Refuses or feels unable to agree to safety plan
Describe:			☐ Sexual abuse (lifetime)
			☐ Family history of suicide (lifetime)
☐	Pending incarceration or homelessness		**Protective Factors (Recent)**
☐	Current or pending isolation or feeling alone		☐ Identifies reasons for living
Treatment History			☐ Responsibility to family or others; living with family
☐	Previous psychiatric diagnoses and treatments		☐ Supportive social network or family
☐	Hopeless or dissatisfied with treatment		☐ Fear of death or dying due to pain and suffering
☐	Non-compliant with treatment		☐ Belief that suicide is immoral; high spirituality
☐	Not receiving treatment		☐ Engaged in work or school
Other Risk Factors			**Other Protective Factors**
☐			☐
☐			☐
☐			☐

Describe any suicidal, self-injurious or aggressive behavior (include dates)

COLUMBIA-SUICIDE SEVERITY RATING SCALE

Screen with Triage Points for ***Outpatient/Ambulatory***

Ask questions that are in bold and underlined.	**Past month**	
Ask Questions 1 and 2	**YES**	**NO**
1) ***Have you wished you were dead or wished you could go to sleep and not wake up?***		
2) ***Have you had any actual thoughts of killing yourself?***		
If YES to 2, ask questions 3, 4, 5, and 6. If NO to 2, go directly to question 6.		
3) ***Have you been thinking about how you might do this?*** e.g. "*I thought about taking an overdose but I never made a specific plan as to when where or how I would actually do it....and I would never go through with it.*"		
4) ***Have you had these thoughts and had some intention of acting on them?*** as opposed to "*I have the thoughts but I definitely will not do anything about them.*"		
5) ***Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?***		
6) ***Have you ever done anything, started to do anything, or prepared to do anything to end your life?*** Examples: Collected pills, obtained a gun, gave away valuables, wrote a will or suicide note, took out pills but didn't swallow any, held a gun but changed your mind or it was grabbed from your hand, went to the roof but didn't jump; or actually took pills, tried to shoot yourself, cut yourself, tried to hang yourself, etc. **If YES, ask:** ***Was this within the past 3 months?***	**Lifetime** **Past 3 Months**	

Response Protocol to C-SSRS Screening

Item 1 Behavioral Health Referral

Item 2 Behavioral Health Referral

Item 3 Behavioral Health Consult (Psychiatric Nurse/Social Worker) and consider Patient Safety Precautions

Item 4 Behavioral Health Consultation and Patient Safety Precautions

Item 5 Behavioral Health Consultation and Patient Safety Precautions

Item 6 Behavioral Health Consult (Psychiatric Nurse/Social Worker) and consider Patient Safety Precautions

Item 6 3 months ago or less: Behavioral Health Consultation and Patient Safety Precautions

Suicide Intervention Check List

Stay Calm	Get the Person to Talk	Listen
Express Concern	Focus on Person's Ambivalence	Reinforce Person's Strengths

Assessment & Management

ENGAGE	*You sound overwhelmed. How are you feeling about all this?*
IDENTIFY	*Are you thinking about suicide? Killing yourself? Taking all your pills?*
INQUIRE	*What has been going on for you? How has it come to this point?*
AMBIVALENCE	*Part of you feels suicide is the only answer, but part of you is still looking for another way.*

	Plan	Prior Attempts	Location	Resources	Feelings
ASSESS	-How? -When? -How prepared? -How lethal?	-Prior ideation -Modelling after family	-Alone? -Where?	-Internal -External	-Hopeless -Helpless -Loss

I see you at (high, moderate, low) risk of harming yourself right now. Do you agree?

Prevent

CONTRACT	LIMIT ACCESS TO METHOD	REACH OUT TO RESOURCES	CALL 9-1-1
No self harm			Immediate high risk

If you assess the risk of suicide to be...

Low Risk	Moderate Risk	High Risk
-No particular changes -Recurrent risk assessment as indicated by circumstances and clinical presentation of client	-Recurrent evaluation -May see client more often -Re-evaluate treatment goals -Make client aware of 24 hour crisis services available -Telephone contact to monitor -Professional consultation -Involve family members	-Immediate evaluation for psychiatric hospitalization (voluntary or involuntary depending on circumstances). -Client should be accompanied and monitored at all times. -Involve family -Involve police as needed

Distress Centre of Ottawa: 613-238-3311
Kids Help Phone: 1-800-668-6868
Tel-Aide Outaouais: 819-741-6433
Mental Health Crisis Line: 1-866-996-0991

Appendix J

Super-ordinate Themes with Subsets from Three Focus Groups

Focus group 1	Focus group 2	Focus group 3
1.a Experience living with CF (RD) day-to-day - symptoms and treatments	1.a Experience living with CF (RD) day-to-day - symptoms and treatments	1.a Experience living with CF day-to-day - symptoms and treatments
1.b Experience living with CF(RD) day-to-day - interpersonal relationships	1.b Experience living with CF (RD) day-to-day - interpersonal relationships	1.b Experience living with CF day-to-day - interpersonal relationships
	1.c Experience living with CF (RD) day-to-day - early and late diagnosis	
	1.d Experience living with CF (RD) day-to-day - impact on career	
		1.e Experience living with CF day-to-day - CF as spectrum
		1.f Experience living with CF day-to-day - CF can be a dark disease
1.g Experience living with CF (RD) day-to-day - CF and the impact of COVID		1.g Experience living with CF day-to-day - CF and the impact of COVID

Focus group 1	Focus group 2	Focus group 3
	1.h Experience living with CF (RD) day-to-day - Trikafta (this magic pill)	
	1.i Experience living with CF (RD) day-to-day - CF camp	
2.a Psychological Impact of CF (RD) - interrelationship of physical and mental health		2.a Psychological Impact of CF – interrelationship of physical and mental health
2.b Psychological Impact of CF(RD) - isolation from others with CF	2.b Psychological Impact of CF (RD) - isolation from others with CF	2.b Psychological Impact of CF - isolation from others with CF
	2.c Psychological Impact of CF (RD) - not feeling good enough	
3.a CF (RD) as a non-visible illness/disability – walking a line between sick and not sick		
	3.b CF (RD) as a non-visible illness/disability – Concealment vs Disclosure (treatments and identity)	

Focus group 1	Focus group 2	Focus group 3
		3.c CF as a non-visible illness/disability - the ignorance of people
4. CF (RD) and sense of self/identity	4. CF (RD) and sense of self/identity	4. CF and sense of self/identity
5. CF (RD) positive aspects and meaning and purpose in life	5. CF (RD) positive aspects and meaning and purpose in life	5. CF positive aspects and meaning and purpose in life
6.a Observations and recommendations - for CF (RD) counsellors/ psychotherapists - - attitude, knowledge, and skills	6.a Observations and recommendations - CF (RD) counsellors/ psychotherapists – attitude, knowledge, and skills	6.a Observations and recommendations - CF counsellors/ psychotherapists - attitude, knowledge, and skills
6.b Observations and recommendations - CF (RD) doctors, nurses, and all allied health	6.b Observations and recommendations - CF (RD) doctors, nurses, and all allied health	6.b Observations and recommendations - CF doctors, nurses, and all allied health
		6.c Observations and recommendations - healthcare system

Focus group 1	**Focus group 2**	**Focus group 3**
7.a Counselling and psychotherapy experiences - helpful experiences	7.a Counselling and psychotherapy experiences - helpful experiences	7.a Counselling and psychotherapy experiences - helpful experiences
7.b Counselling and psychotherapy experiences - unhelpful experiences		7.b Counselling and psychotherapy experiences - unhelpful experiences
8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results	8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results	8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results
8.b Feedback and suggestions re: PAR methodology - fostering a sense of community	8.b Feedback and suggestions re: PAR methodology - fostering a sense of community	8.b Feedback and suggestions re: PAR methodology - fostering a sense of community

Appendix K

Super-ordinate Themes with Subsets from Six Semi-structured Interviews

Charlene (Nov.5, 2020)	**Kyle (Nov.10, 2020)**	**Alice (Nov.10, 2020)**	**Jake (Nov. 11, 2020)**	**Karen (Nov.17, 2020)**	**Veronica (Nov.24, 2020)**
	1.a Experience living with CF day-to-day - symptoms and treatments	1.a Experience living with CF (RD) day-to-day - symptoms and treatments	1.a Experience living with CF(RD) day-to-day - symptoms and treatments	1.a Experience living with CF day-to-day - symptoms and treatments	1.a Experience living with CF (RD) day-to-day - symptoms and treatments
1.b Experience living with CF day-to-day - interpersonal relationships	1.b Experience living with CF day-to-day - interpersonal relationships	1.b Experience living with CF (RD) day-to-day - interpersonal relationships	1.b Experience living with CF(RD) day-to-day - interpersonal relationships	1.b Experience living with CF day-to-day - interpersonal relationships	1.b Experience living with CF (RD) day-to-day - interpersonal relationships
1.c Experience living with CF day-to-day - impact on career	1.c Experience living with CF day-to-day - impact on career	1.c Experience living with CF(RD) day-to-day - impact on career	1.c Experience living with CF (RD) day-to-day - impact on career		1.c Experience living with CF(RD) day-to-day - impact on career
				1.d Experience living with CF day-to-day - CF as spectrum	

Charlene (Nov.5, 2020)	**Kyle (Nov.10, 2020)**	**Alice (Nov.10, 2020)**	**Jake (Nov. 11, 2020)**	**Karen (Nov.17, 2020)**	**Veronica (Nov.24, 2020)**
1.e Experience living with CF day-to-day - illness/ disability and healthcare bureaucracy					
				1.f Experience living with CF day-to-day - significant cognitive impact	
				1.g Experience living with CF day-to-day - existential responsibility	
1.h Experience living with CF day-to-day - CF and the impact of COVID		1.h Experience living with CF(RD) day-to-day - CF and the impact of COVID			1.h Experience living with CF(RD) day-to-day - CF and the impact of COVID
	2.a Psychological Impact of CF - Stigma		2.a Psychological Impact of CF (RD) - Stigma		2.a Psychological Impact of CF(RD) - Stigma

Charlene (Nov.5, 2020)	**Kyle (Nov.10, 2020)**	**Alice (Nov.10, 2020)**	**Jake (Nov. 11, 2020)**	**Karen (Nov.17, 2020)**	**Veronica (Nov.24, 2020)**
2.b Psychological Impact of CF - emotional characteristics		2.b Psychological Impact of CF(RD) - emotional characteristics	2.b Psychological Impact of CF(RD) - emotional characteristics	2.b Psychological Impact of CF - emotional characteristics	2.b Psychological Impact of CF(RD) - emotional characteristics
2.c Psychological Impact of CF - the role of others		2.c Psychological Impact of CF(RD) - the role of others	2.c Psychological Impact of CF(RD) - the role of others	2.c Psychological Impact of CF - the role of others	2.c Psychological Impact of CF(RD) - the role of others
			2.d Psychological impact of CF (RD) - transplant experience and existential concerns		
			2.e Psychological Impact of CF(RD) - isolation from others with CF	2.e Psychological Impact of CF - isolation from others with CF	2.e Psychological Impact of CF(RD) - isolation from others with CF
2.f Psychological Impact of CF - vulnerability versus control	2.f Psychological Impact of CF(RD) - vulnerability versus control	2.f Psychological Impact of CF(RD) - vulnerability versus control	2.f Psychological Impact of CF(RD) - vulnerability versus control	2.f Psychological Impact of CF - vulnerability versus control	2.f Psychological Impact of CF(RD) - vulnerability versus control

Charlene (Nov.5, 2020)	**Kyle (Nov.10, 2020)**	**Alice (Nov.10, 2020)**	**Jake (Nov. 11, 2020)**	**Karen (Nov.17, 2020)**	**Veronica (Nov.24, 2020)**
3. CF as a non-visible illness/ disability - concealment versus disclosure	3. CF as a non-visible illness/ disability - concealment versus disclosure	3. CF(RD) as a non-visible illness/ disability - concealment versus disclosure	3. CF (RD) as a non-visible illness/ disability - concealment versus disclosure	3. CF as a non-visible illness/ disability - concealment versus disclosure	3. CF(RD) as a non-visible illness/ disability - concealment versus disclosure
4. CF and sense of self/Identity	4. CF and sense of self/Identity	4. CF(RD) and sense of self/Identity	4. CF (RD) and sense of self/Identity	4. CF and sense of self/Identity	4. CF(RD) and sense of self/Identity
5. CF positive aspects and meaning and purpose in life	5. CF positive aspects and meaning and purpose in life	5. CF(RD) positive aspects and meaning and purpose in life	5. CF (RD) positive aspects and meaning and purpose in life	5. CF positive aspects and meaning and purpose in life	5. CF(RD) positive aspects and meaning and purpose in life
6.a Observations and recommendations - CF counsellors/ psychotherapists - attitude, knowledge, and skills	6.a Observations and recommendations - CF counsellors/ psychotherapists - attitude, knowledge, and skills	6.a Observations and recommendations - CF(RD) counsellors/ psychotherapists - attitude, knowledge, and skills	6.a Observations and recommendations - CF (RD) counsellors/ psychotherapists - attitude, knowledge, and skills	6.a Observations and recommendations - CF counsellors/ psychotherapists - attitude, knowledge, and skills	6.a Observations and recommendations - CF(RD) counsellors/ psychotherapists - attitude, knowledge, and skills
6.b Observations and recommendations - CF doctors, nurses, and all allied health - integrating mental health	6.b Observations and recommendations - CF doctors, nurses, and all allied health - integrating mental health	6.b Observations and recommendations - CF(RD) doctors, nurses, and all allied health - integrating mental health	6.b Observations and recommendations - CF (RD) doctors, nurses, and all allied health - integrating mental health	6.b Observations and recommendations - CF doctors, nurses, and all allied health - integrating mental health	6.b Observations and recommendations - CF(RD) doctors, nurses, and all allied health - integrating mental health

Charlene (Nov.5, 2020)	**Kyle (Nov.10, 2020)**	**Alice (Nov.10, 2020)**	**Jake (Nov. 11, 2020)**	**Karen (Nov.17, 2020)**	**Veronica (Nov.24, 2020)**
7.a Counselling and psychotherapy experiences - helpful experiences	7.a Counselling and psychotherapy experiences - helpful experiences	7.a Counselling and psychotherapy experiences - helpful experiences	7.a Counselling and psychotherapy experiences - helpful experiences	7.a Counselling and psychotherapy experiences - helpful experiences	7.a Counselling and psychotherapy experiences - helpful experiences
	7.b Counselling and psychotherapy experiences - unhelpful experiences	7.b Counselling and psychotherapy experiences - unhelpful experiences			
8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results	8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results	8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results	8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results	8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results	8.a Feedback and suggestions re: PAR methodology - general comments and dissemination of results
8.b Feedback and suggestions re: PAR methodology - fostering a sense of community	8.b Feedback and suggestions re: PAR methodology - fostering a sense of community	8.b Feedback and suggestions re: PAR methodology - fostering a sense of community		8.b Feedback and suggestions re: PAR methodology - fostering a sense of community	8.b Feedback and suggestions re: PAR methodology - fostering a sense of community

Appendix L

A Comparative Analysis of Focus Group PHQ-9 and GAD-7 Scores

PHQ-9 Scores

PHQ-9 scores across focus groups varied with focus group one having the highest scores overall followed by focus group three and then focus group two. Focus group one scores ranged from 17 (moderately severe) to six (mild), with a mean score of 11 (moderate). Fully 4/6 or 67% of co-researchers in focus group one scored within the moderate (10 -14) to moderate-severe (15-19) range citing their problems as anywhere from "somewhat difficult" to "very difficult" in terms of "how difficult problems made it to do work, take care of things at home, or get along with other people." Two co-researchers answered affirmatively to question nine, "Thoughts that you would be better off dead or hurting yourself in some way." This required follow up intervention by this researcher: a suicide risk assessment, ensuring medication monitoring and ongoing counselling/psychotherapy support. This is contrasted with focus group three where scores ranged from nine (mild) to three (none -minimal), with a mean score of six (mild). Fully 5/7 or 71 % of co-researchers scored within the mild range (five - nine) citing their problems in life domains mostly as "not difficult" to "somewhat difficult" with one marking "very difficult." Lowest scores are seen in focus group two where scores ranged from seven (mild) to zero (none-minimal), with a mean score of five (mild). Fully 4/5 or 80% of co-researchers scored within the mild range (five-nine), marking their problems in life domains as "not difficult at all" and "somewhat difficult." Due to the low PHQ-9 scores of co-researchers in focus groups three and two and no affirmative answers to question nine no further intervention had been warranted on the part of this researcher.

Other outstanding features across focus groups include most co-researchers marking affirmative to question four, "Feeling tired and having little energy." Other somatic markers

include 83% of co-researchers in focus group one marking affirmative to question five, “Poor appetite or overeating” as compared to 40% and 30% in focus groups two and three, respectively. As well, fully 83% of co-researchers in focus group one marked affirmative to question six, “Feeling bad about yourself – or that you are a failure or have let yourself or your family down,” followed by 40% of co-researchers in focus group two and 86% of co-researchers in focus group three. Taken together the overall PHQ-9 scores for focus group one are higher, with the mean score falling within the moderate range, and inclusive of somatic features such as fatigue and poor appetite, and 83% of co-researchers marking affirmative to question six. It is possible that the higher PHQ-9 scores of co-researchers in focus group one relative to those in the other groups is a consequence of their complex disease compliment and treatment regimen which negatively impacts their quality of life and mood. Again, many of these features are expounded upon in super-ordinate theme 1.a Experience living with CF(RD) day-to-day- symptoms and treatments, and throughout the findings. Focus group three has the next highest PHQ-9 scores, although the mean score falls within the mild range, with fully 86% of co-researchers marking affirmative to question six. Co- researchers in focus group three speak to the capriciousness of their illness and three are employed part-time or on ODSP in part for this reason. One wonders if the high percentage of affirmative answers to question six reflects the difficulty of having to navigate the capriciousness of CF with the developmental tasks of young adulthood and perceiving that one is falling short of expectations. These subject matters are discussed in-depth in super-ordinate themes 1.e Experience living with CF day-to-day – CF as spectrum, and 1.f Experience living with CF day-to-day - CF can be a dark disease, amongst others. Focus group two seems to fare the best with the lowest scores on the PHQ-9 overall as well as low somatic markers, and only 40% marking affirmative to question six. This may be due to “having lived with CF the longest,” “the perspective of age”

as well as being in better physical health. In conclusion, there is an obvious disparity between focus groups not only in terms of unique characteristics but also in terms of their PHQ-9 scores, symptoms cited and the extent to which these functionally impact their lives. Where there is a similarity in findings this may lend credence to results.

GAD-7 Scores

GAD-7 scores were lower than PHQ-9 scores across focus groups, with focus group one having the highest scores followed by focus group two and focus group three. Focus group one scores ranged from 15 (moderate-severe) to four (mild), with a mean score of 8.5 (mild), with co-researchers citing their problems as "not difficult" to "somewhat difficult" and one marking "very difficult" in terms of "how difficult problems made it to do work, take care of things at home, or get along with other people." Focus group two scores ranged from six (mild) to zero (none-minimal), with a mean score of 4.2 (mild) with co-researchers citing their problems in life domains evenly as "not difficult" to "somewhat difficult." Focus group three scores ranged from seven (mild) to two (none-minimal), with a mean score of four (mild) with five co-researchers citing their problems in life domains as "not difficult" and two marking "somewhat difficult." Another discernable pattern across focus groups includes all co-researchers answering affirmatively to one or more of questions one through three related to feeling anxious or worried: question one, "Feeling nervous, anxious, or on edge;" question two, "Not being able to stop or control worrying;" and question three, "Worrying too much about different things." Some anxiety and worry is consistent with living with an unpredictable and life limiting illness (Dezutter et al., 2015; Gray & Fossey, 2003; Juuso et al., 2011; Livneh & Antonak, 2005; Lorenz, 2010; Niemeier, 2008; Psarra & Kleftaras, 2013). Scores taken from questions one through three alone mirror the ranking of PHQ-9 overall scores, with focus group one having the highest score (five, mild) followed by group

three (2.7, none-minimal) and group two (two, none-minimal). Finally, fully 3/6 or 50% of co-researchers in focus group one responded affirmatively to question seven, “Feeling afraid as if something bad might happen,” whereas there were no affirmative answers to this question in either focus groups two and three. In conclusion, while the GAD-7 scores are lower overall, and there is less disparity between focus groups two and three, once again focus group one fares worse than the others in terms of the highest score coupled with affirmative answers to anxiety and worry and to question seven. The reasons for this result may be the poorer overall health of co-researchers coupled with the developmental tasks of young adulthood and other undetermined factors.