

“I wish people would understand”: exploring ableism through young adults’ experiences of
living with chronic illness

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ABSTRACT

The purpose of this qualitative research project is to highlight the diversity of lived experiences of young adults living with chronic illnesses and to interpret the meaning attributed to these experiences. More specifically, the objectives of this study are: 1) to describe how young adults with chronic illness perceive their relationships and their social environment; 2) to identify and describe the specific challenges and oppression experienced by young adults with chronic illness; 3) to identify the strategies developed by young adults to cope with social expectations; 4) to explore how young adults with chronic illness perceive some of their experiences as positive; and 5) to propose implications for social work practice and suggest appropriate intervention methods. Data was collected by interviewing seven young adults with chronic conditions in the Ottawa region and the results were analyzed through the combined lenses of a social constructionist view disability and the phenomenology of impairment. The results of this study show that central to the experiences described by participants is discrimination resulting from ableist expectations. More specifically, the key findings demonstrate that because of dominant ableist and healthist ideologies, young adults with chronic illness experience internalized ableism. Anti-oppressive social work is proposed to challenge discrimination and address some of young adults' needs as well as to make changes on a more structural level through collective action, advocacy, policy change and activism.

Keywords : young adults, chronic illness, disability, ableism, discrimination, social construction of disability, phenomenology of impairment, anti-oppressive social work

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INTRODUCTION

In contemporary Western society, reminders of the importance of healthy living to ensure optimal health and well-being are daily occurrences. Whether it be through physical activity, healthy eating or a wide range of behaviours, Canadians are constantly encouraged to develop skills to ensure optimal health, well-being and reduce risk of disease and illness. Is it safe to assume that with this increased focus on self-management and work on oneself, we lack the necessary skills to manage our health and/or illnesses? Or rather, is this hyper-focus on individual management and responsibility representative of societal conceptions that consider illness and disability as a personal ailment that requires to be better managed? While these questions have no clear-cut answers, it seems relevant to explore the social context of self-management approaches and programs that have emerged to address chronic illness. More specifically, this research will explore how chronic illness is lived differently (or similarly) by young adults while recognizing the importance of context within which experiences are produced. The study seeks to answer the following question: How do young adults with chronic illness experience their illness and what meaning do they attribute to their experiences?

The thesis will be divided in five sections. The first chapter will present the research problem and provide an overview of existing literature on important concepts such as disease and illness, healthism and ‘young adult’. The following chapter will propose social constructionist analysis of disability and the phenomenology of impairment as a conceptual framework. The third chapter will describe the semi-directed interview and thematic analysis as the chosen data collection and analysis techniques. The fourth chapter will provide analysis of data as well as a discussion of results. The final chapter will propose implications for social work practice.

Self-reflective considerations

My specific focus on the social construction of disability and illness has come from personal experiences of living with chronic migraines for the last decade (an episodic disability that, in my case, results in the significant loss of function for several hours, several times a month). Although health-care professionals have diagnosed my condition as a ‘incurable’ yet manageable genetic neurological ‘disease’, the pressure to become well and to better manage my condition has been particularly disabling, at times more so than the physiological dimensions of my illness. Continuously encouraged and expected to try the latest treatment, medication or miracle solution by friends, family and society at large has often unknowingly contributed to making the illness my

responsibility and has pointed to its undesirability and inconvenience. During particularly difficult times, I reached out for support and was often discouraged by the lack of support and services for people with chronic illness, as well as the preferred self-management approaches that exist. Learning how to meditate, manage anxiety and live a healthy lifestyle were some of the only available activities of support in which I participated in time and again. However, I quickly realized the extent to which they did not meet my needs. Where were the groups addressing the process of acceptance, the disabling nature of living in a society that is unforgiving and fixated on ‘cures’? How about support groups focusing on the positive aspects with living with a disability, the pride of disability identity, the social perceptions and stigma associated of living with a chronic illness?

Progressing towards self-acceptance has proven to be a continuous and challenging process that has been particularly difficult, especially when living within a culture that values health and absence of disease and/or impairment. Over the years and as a result of my experiences, I have learned to appreciate the value in identifying as a disabled young woman. My disabled identity has fluctuated; sometimes it has been positive and empowering and at times it has been a source of oppression, but I do not consider the current cultural context to have encouraged the development of a disabled identity.

There are several reasons why I have included these considerations on my disability experience. Firstly, I consider it as one of the many important and valuable experiences that are often silenced, misunderstood or invalidated within people living with chronic illness. Rather than speaking on behalf of all young adults with chronic illness, I share this experience to demonstrate the need to consider different perspectives to better understand the diversity of experiences in a much larger context. Secondly, this is a way to show transparency and establish a clear standpoint. Taking into consideration the subjective nature of qualitative research within social sciences, it serves as a reminder of how experiences are highly dependent on context, social interactions and environments. By adopting this critical perspective to analyze and understand the studied phenomenon, I have chosen to acknowledge my biased and subjective approach to research and to consider it as only one perspective among many.

CHAPTER 1: RESEARCH PROBLEM

1.1 Defining concepts: chronic disease or chronic illness?

It is not uncommon to hear various terms used to describe chronic health issues; chronic *disease*, chronic *illness* and chronic *pain* are some of the most commonly used terms to describe ongoing chronic conditions. It is important to clarify the distinction between these terms as they have different meanings and represent how health is popularly understood, how society *conceives* illness and consequently, designs programs and services in the community. Although the concepts of *health*, *disease* and *illness* have been contested, debated and highly theorized over the years, I will explore the ordinary use of the words.

The term *disease* is typically used to refer to some medically recognized diagnostic categories of physical and mental ‘abnormality’ (Wendell, 2017). The understanding of illness as a disease stems from the biomedical model that arose during the mid and late 19th century and that perceives it as an “alteration in biological structure” (Kleinman, 1988: 5) (Bury, 2001). This conception of disease focuses on technical and physiological issues in terms of disorders and is often centred on a diagnosis. With the rise of the medical model of disease, the experience of illness has focused on specific biological causes and considered disease as a deviation from the ‘normal’ or the individual’s ‘natural state’ (Kleinman, 1988). It is through perceiving ‘diseases’ as medical problems that contemporary Western society has come to understand and represent illness: as physical, biological unwanted ailments that need to be cured and that require first and foremost medical attention (Conrad, 2005). Within disability studies, this model is commonly referred to as the ‘medical model of disability’. Authors such as Crow (1996) Hughes and Paterson (1997) Shakespeare (2010) and Wendell (1996a), have extensively argued that this historically predominant model is still continuously reproduced within contemporary Western society. When the government of Canada (i.e. public health) speaks of chronic conditions, they typically refer to the four major and physical ‘chronic diseases’ which include CVD (cardiovascular diseases), cancer, CRD (chronic respiratory diseases) and diabetes (Public Health Agency of Canada, 2016). The terms ‘condition’ and ‘disease’ are often used synonymously, both to designate ‘biomedical diseases’ based on diagnosis or disease classification.

The term *illness* is more commonly used to refer to people’s experiences of suffering and perceptions of disease (Almeida-Filho, 2013). Contrary to the biomedical conception of disease, illness refers to the various dimensions of disability that can arise as a result of disease or other disabling conditions (Kleinman, 1988). Although definitions of chronic illness vary, they are

typically understood as illnesses that persist beyond three to six months, cannot be ‘cured’ and will not result in death in the near future. Social, biological and psychological dimensions are to be considered to understand the experience of illness (Scambler, 2010). Recognition that illness can be experienced various ways exists through symptoms such as pain or nausea, through disruptions of daily activities, routines or even through more subjective dimensions of experience. Within this perspective, there has been a particular interest in the various social aspects of disease and the experiences of living with a chronic condition that can be disabling. The concept of *sickness* has also been used to refer to the “societal reaction to problems deriving from both disease and illness” (Almeida-Filho, 2013: 436). More specifically, research on chronic illness has largely emerged from the fields of medical sociology and disability studies and have used social constructionist theories as well as labelling theories of deviance to analyze the experience of illness (Scambler, 2010).

Within medical sociology, a significant amount of research has been done on interpersonal interactions from a social deviance paradigm on the disruptions of illness as a ‘personal tragedy’ of becoming ill, as well as on the consequences of medical labelling and diagnosis on the identity of those affected (Thomas, 2010). There has been a particular interest on the everyday experience of illness and people's perceptions of ‘illness’ which are seldom identical to the medical conceptions of ‘disease’ (Friedson, 1970). Within disability theory, there has been emphasis on the social oppression paradigms of chronic illness and disability (Goodley, 2017). Contrary to the medical model of disability, the social model of disability considers oppressive institutions and policies, prejudiced attitudes, discrimination and other social injustices as often being more disabling than the impairment experienced by individuals with a disability and/or chronic illness (Wendell, 2010). In this sense, difficulties related to illness are often created as a result of oppressive institutions and social injustices that either create or worsen impairment or the experience of illness (Conrad, 2005). It is through these approaches that illness has been understood beyond the strictly biomedical perspective.

It seems important to make the distinction between the above mentioned concepts of *disease*, *sickness* and *illness* not only because there is a social component to illness and disability but also because there are many conditions that are not easily diagnosed, understood or recognized by the medical world or society at large. For instance, fibromyalgia and/or chronic fatigue are conditions that have historically been dismissed because the causes of pain and suffering are not

easily identified and consequently not well understood by the medical world (and often not even diagnosed) (McCarberg et al., 2009). In similar situations, a person might be experiencing significant impairment and/or suffering but might not receive recognition for their symptoms as their condition is not medically recognized as a disease or is simply misunderstood by medicine. I would like to suggest that the classification of chronic ‘disease’ is not particularly useful terminology in the way that it is currently understood as it encourages inadequate and inappropriate interventions centred on physical and medical conceptions of disability. This general usage and understanding of chronic illness as disease has generally resulted in medical interventions focused on prevention and treatment of typical understandings of disease. The following section will explore the value of considering social oppression paradigms and of chronic and disabling conditions.

1.2 Chronic and disabling conditions as social oppression

Thomas (2007) refers to *Disablism* as “the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorized as ‘impaired’ by those deemed ‘normal’” (Thomas, 2007: 37). According to the author, this constitutes a form of social oppression alongside sexism, racism, ageism and homophobia but that is often experienced by people who have a chronic illness or condition, whether or not they self-identify as ‘disabled’. *Disablism* may manifest itself in institutionalized and other socio-structural forms and is often reflected in the physical and social organization of society. Thus, the author mentions that we live in a world with expectations: where the ideal of life is to be ‘healthy’, able-bodied, heterosexual, young, ‘ideally-shaped’, English-speaking, etc. These imaginary ‘ideals’ result in the exclusion and marginalization of people with chronic conditions because they often cannot live up to these paradigms and take part in major aspects of life. Some of the barriers disabled people encounter include inaccessible education systems and working environments as well as inadequate and discriminatory health and social support services. A common expectation in the previously stated environments is related to the pace of life in society, that is, social expectations of performance and pressure to conform and adapt to a ‘normal’ pace of life. In the context of young adults, the pressure to work full-time or to enroll in post-secondary education on a full-time basis while maintaining social relationships and other obligations are some examples of what many people with chronic conditions have difficulty conforming to; these situations often results in their exclusion. The “normative and normalizing expectations of pace and scheduling” (Kafer, 2013:

27) points to the reality that many disabled people feel the pressure to conform and adapt to a ‘normal’ pace of life to ‘fit in’ or ‘keep up’ with expectations. For young adults, illness presents itself as another hurdle to conform to social expectations.

Kattari et al. (2018) explore the role that cultural practices play in shaping *ableism*. The authors speak of “ableist body policing experiences” to refer to ways family members, coworkers and the general public police the bodies of people with chronic conditions and disabilities (Kattari et al., 2018 : 486). Through attitudes, comments and practices, people in our social environment are quick to express disbelief in the conditions they do not understand, assuming they are “lazy or over-exaggerating their condition(s)” (Kattari et al., 2018 : 486) In public places, employment settings, educational venues, and in the privacy of one’s home, people often feel as though they need to prove to others that they are ‘disabled’ enough and justify their symptoms and/or conditions and provide explanations when they are unable to live up to social expectations. This can also be experienced in the workplace or in educational institutions when people need to prove their disability to employers, staff or faculty to justify a medical condition or to qualify for accommodations.

Finally, it is not uncommon for people with disabilities and chronic conditions to internalize the oppression they experience, commonly referred as ‘internalized ableism’ (Kattari et al., 2018). This refers to individuals’ frustration with their ‘inability’ to conform to the ability expectations of society. This form of internalized oppression can manifest itself through thoughts, beliefs, comments or everyday interactions. For example, one could feel shamed, frustrated or stigmatized for failing to adapt to expectations and come to believe oppressive comments and to doubt their own abilities (ibid). The next section will explore the emergence of a prominent approach within contemporary Western society in both medical and community-based settings to address chronic illness with self-management.

1.3 Healthism and self-governance as means of addressing chronic illness

In contemporary Western society, the overwhelming preoccupation with bettering oneself takes various forms and is present in many fields such as relationships, health, career, nutrition, etc. Within health and chronic conditions, there is interest in the prevention and treatment of medical diseases, notably through lifestyle changes. Through different self-regulation techniques and practices, it is the individual who is expected to take control of their health, be an actively engaged

patient while complying with normative self-care practices (Broom et al., 2014). Similar individual-oriented approaches to health and illness can be understood through the ideology of 'healthism' (Crawford, 1980; Gibson et al, 2015).

Healthism refers to the preoccupation with personal health as the primary focus for the "definition and achievement of well-being" which is attained primarily through the modification of lifestyles (Crawford, 1980 : 368). It is in this 'healthist' context that health has "become constructed as an individual's responsibility and as an 'unstable property, something to be constantly worked on' (Gibson et al., 2015: 132). During the latter half of the 20th century, cultural shifts such as feminism, neoliberalism, consumerism as well as an increased interest in alternative practices shifted the 'traditional' role of medicine from considering the patient only as a patient to seeing the patient as having a key role in managing their conditions (Broom et al., 2014). The traditional role of medicine and of the 'expert' (biomedical) healthcare was replaced with "the concept of self-governance, casting individuals as responsible for monitoring their own bodies and health" (Crawford, 1980). According to Ehrenberg (1998), it is more specifically during the 1980's that the social discourse surrounding personal responsibility, autonomy and initiative emerged. From then on, individuals have become experts in the management of their lives and must continuously make well-considered choices and decisions to ensure the best outcome for their health and well-being (Roy, 2015). It is important to note that while there is a shift in the health movement, healthism (like medicine) continues to situate the problem and many of the 'solutions' of health and disease at the level of the individual (Crawford, 1980.) Broom et al., (2014) speaks of a "plural medico-cultural 21st century" to refer to the current model of health and well-being that is torn between individual and state responsibilities.

The ideology of healthism also incorporates the concept of self-governance (Crawford, 1980). Alluding to the works of Foucault (1984, 2001) and Goffman (1973a, 1973b), Roy (2015) argues that there are two underlying dimensions to self-governance. On the one hand, it refers to a person's ability to take control of their health through their actions and behaviours. On the other, it refers to various "power systems" that influence one's ability to take control of their health. For example, within contemporary Western society, each person is held responsible to apply various 'preventive' strategies in order to prevent 'common' diseases (e.g. the three "F"'s: Feet (exercise), forks (diet), fingers (smoking)). Although choosing to engage in 'healthy behaviours' such as having a well-balanced diet or exercising could be interpreted as strictly personal choices, it is

important to consider the social pressures that influence or guide self-governance. If someone becomes ill or unwell and is unable to maintain what is socially expected of them (for example maintaining responsibilities such as going to work or school or maintaining social roles such as being a mother, etc.), they are held accountable and are socially required to “demonstrate their ability to maintain health or otherwise account for their ill health”(Broom et al., 2014: 133). Healthism introduces and maintains discourses of morality, notably through social interactions when people (such as friends or health-care professionals) monitor your behaviours, your habits, your self-management skills and behaviours. It is important to consider how these interactions are mired in the ideology of healthism (larger societal expectations and pressures) (Crawford, 1980). Self-responsibility alone does not necessarily equal blame, but it does so with the help of an ideology focused on behaviour, motivation and emotional state that insists that “change and health derive from the individual choices, and poor health is most likely to be seen as deriving from individual failings” (Crawford, 1980: 378). There are a number of external factors such as obstacles in access to care, financial constraints and discrimination that could influence a person’s commitment to self-manage, yet individuals are continuously held solely responsible for the continuation of their illness or their self-management abilities (Attali, 2014; Crawford, 1980; Roy, 2015).

I will share a personal experience as I think it is a good example of how discourses of morality can be reproduced in health care institutions. Several years ago, I was enrolled in a 12-week anxiety self-management program at my local hospital. At the very first session, the facilitators had informed the group that there was a policy stating that participants could not miss more than three sessions, as this was a ‘treatment’ group and in order to get the maximum benefits from therapy, at least 9 sessions needed to be completed. As I have an unpredictable and episodic condition, this was concerning to me and I made sure to discuss with the Social Worker in charge of the group about possible accommodations if I could not attend due to illness. Regrettably, the Social Worker made it clear that the program was not flexible and that the 3 session attendance was mandatory, which meant my only option was to continue to attend until I had missed too many sessions and that at that point, I would need to withdraw from the program. This did in fact occur, and I could not complete the program. I put my name down for the following group several months later. Several weeks into my second run of the program, I missed several sessions due to illness but more worryingly, I was experiencing a lot of anxiety. This anxiety was overshadowed by the

guilt I was feeling regarding my ‘inability’ to commit to the self-management program. My ‘inability’ to stick to the program had nothing to do with my lack of motivation, drive or responsibility; it had to do with the fact that I was unable to attend all of the sessions due to illness.

In this instance, the hospital represents a good example of how institutions have an important role in creating and maintaining normative discourses of self-management that can result in further discourses of morality. The program’s rigid structure implied that everyone should be participating (or should be doing their best) to participate under normative pre-established guidelines and that failure to do so represented an individual problem. Even after voicing my concerns, offering potential solutions and writing formal complaints to the hospital, I was not given any accommodations and/or responses. The following section will explore programs targeted more specifically at the self-management of chronic illness and pain.

1.4 Self-management programs for chronic illness and pain

Across Canada and globally, given the large and growing proportion of people with chronic and multiple chronic conditions, health care organizations have developed self-management support to address increasing needs (Health Ontario, 2012). The first self-managing programs emerged in the early 2000’s in California as an alternative response to traditional interventions that placed healthcare professionals in roles of authority and placed patients in passive roles (Bury et al. 2005). According to Scambler (2010), self-management appeared at a time where “governments were promoting neoliberal or post welfare individualized consumer choice and responsibility” (Scambler, 2010 : 4) rather than the more collectivist approaches characteristic of the post-war welfare state. With regards to chronic and disabling conditions, this meant considerable emphasis on personal responsibility and state ‘help’ to encourage individuals to take control of their illnesses (ibid). According to Scambler (2010), self-management provides an “ideological cover for politically motivated policies designed to cut service demand” (p.4), especially within hospital-based treatment and care. Although self-management may appear to encourage empowerment and the ‘liberal aspirations to autonomy’, they are in fact motivated by neoliberalist agendas (ibid). An understanding of the social changes on a more macro-level clarifies the circumstances in which these programs were developed and the criticism they have received for their inability to cater to the needs of people with chronic illnesses.

From a policy and healthcare delivery perspective, the Health Council of Canada (2012) refers to self-management as “the tasks that an individual must undertake to live well with one or

more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions” (p.7). Essentially, the self-management approach focuses on enabling ‘sufferers’ of chronic illness to gain motivation and/or skills needed to improve their condition management (Bury, 2005). With this approach growing in popularity, there have been several programs developed throughout Canada, more particularly in hospital settings, family health centres, non-profit health associations and community health centres, many of them being provincially funded programs (Lawn et al., 2011). These programs generally have a very well-defined and predetermined structure consisting of workshops that emphasize practical ‘how-to’ techniques. As indicated in the *Living a Healthy Life with Chronic Conditions* workshop outline, the six sessions explore the following topics: Getting a Good Night’s Sleep, Introduction to Physical Activity and Exercise, Preventing Falls and Improving Balance, Pain and Fatigue Management, Endurance Exercise, Healthy Eating, Communication Skills, Making Healthy Food Choices, Weight Management, Medication Usage as well as Positive Thinking (Living Healthy Champlain, 2018). Following every workshop, participants are required to make an action plan which consists of specific and attainable goals for the week ahead that include how they will put into action what has been learned during the sessions.

Because of self-management programs (SMP) increasing popularity worldwide, there has been interest within academia to understand their effectiveness. Uncertainty remains about the usefulness of the programs. Some researchers affirm that their effectiveness has been overstated and that the benefits gained are essentially short-term (Foster et al, 2007; Bury, 2005). Other criticisms of the approach are that SMPs are located in a more individualistic and psychological framework, where an individual’s ability to manage their own illness as well as their symptoms is prioritized (Bury, 2010; Johnston et al., 2012; Scambler, 2010; Wendell, 2017). Personal growth, autonomy and empowerment are valued but this has been criticized for its inability to understand the socially contextualized nature of living with a chronic illness that is not located in individual responsibility (Bury, 2010). Although the workshops explore various components of living with chronic conditions, several researchers have argued that they are very much focused on ‘self-efficacy’ and skills to be acquired by individuals (Newbould, Taylor and Bury, 2006). Indirectly, this approach may imply that people with chronic health conditions are lacking knowledge, education, skills, motivation or even confidence to manage the impacts of their condition.

Although the Health Council of Canada (2012) claims that there is evidence supporting the success of SMP in helping patients manage their symptoms, there appears to be very little research to support these claims (Johnston et al, 2012).

Another criticism has been that patients are considered as experts while also needing education because of their lack of knowledge and/or skills. The idea of judging patients as ‘experts’ and ‘non-experts’ or ‘successful’ or ‘unsuccessful’ in managing their illness is problematic because it holds people responsible for the improvement or deterioration of their conditions (Bury, 2010). Further, research has shown that most people who sign up to join chronic disease SMP are already ‘good managers’ and don’t necessarily need to be ‘taught’ skills on how to better manage their illness (Bury, 2010). Bury (2010) also argues that the self-management approach “involves moving the focus away from the contextualized nature of living with a chronic illness to one where specified skills to be acquired by individuals are adumbrated and prescribed” (Bury, 2010 : 171).

Contrary to some of the criticism raised in the literature, several studies have pointed to the more positive and potentially beneficial aspects of SMPs (McGowan, 2011). Some of the positive outcomes reported are “small to moderate improvements” in participants’ self-efficacy (more confidence about self-managing), psychological health (less stress and depression), and health behaviours (better cognitive symptom management and communication with physicians). Many of these improvements were sustained for up to one year” (Centers for Disease Control and Prevention, 2011). The positive outcomes are largely focused on behavioural change and some financial advantages for healthcare and government institutions. In Ontario, a study conducted in 2012 aimed to better understand participants' experiences in the Stanford CDSMP workshop (Johnston et al., 2012). Focusing mostly on behaviour changes and the success rate of the program, the study concluded that people who participated in the program reported a positive change in physical activity patterns, an improved sense of social connection and better self-managing skills (ibid).

Finally, there appears to be a consensus among most studies that further research should be conducted in key areas such as how to best sustain program effects over the long term (Health Council of Canada, 2011). Additionally, there is very little evidence supporting patients increased ability to reduce disease-related effects as well as the reduced use of health services because of improved behaviours and management (Foster et al, 2007). The degree, duration and effect of these

programs are still unclear (Johnston et al., 2012). Also, there is little published evidence on the impact of SMPs on the health-care system.

This review of the literature shows that there are varying opinions on the benefits of SMPs. An important observation is the discrepancy between the experiences, needs and realities of individuals with chronic illnesses and the programs that are put in place to address these same issues. It seems that SMPs are mostly focused on individual management whereas people living with chronic illness require much more complex interventions.

1.5 Young adults with chronic illness, an invisible reality?

As previously stated, the Canadian Public Health agency has primarily represented chronic illness in Canada on the basis of the biomedical conception of ‘disease’, notably because the four most pervasive physical conditions (CVDs, cancers, CRDs and diabetes) represent the leading causes of death in Canada and are considered preventable (Public Health Agency, 2016). This has resulted in a specific interest in the ageing population, notably because one in six Canadians are 65 years or older and the age group is growing four times faster than the overall population (ibid). Although this a justified and important concern, little research has been conducted on the prevalence of chronic illnesses among younger adults despite the fact that information about the risks of chronic disease among young adults is readily available. Data linking chronic diseases to risks such as tobacco smoking, physical inactivity, unhealthy eating, harmful use of alcohol and sedentary behaviours is readily available (Public Health Agency of Canada, 2016; Public Health Ontario, 2012). Additionally, information pertaining to specific health conditions (such as cancer, epilepsy, celiac etc.) is also easily available. Also, most of the self-management literature has been focused on older populations, although chronic illness profoundly affects adolescents and young adults (Sawyer and Aaroni, 2005). In essence, there is no shortage of reasons to be concerned about how younger individuals are affected by chronic illness or other chronic health conditions.

1.5.1 ‘Young adult’, is there such a thing?

What do we mean by ‘young’? The terms ‘young adult’, ‘young person’, ‘emerging adult’ appear similar but are in fact, highly theorized and debated concepts that hold several meanings and varying interpretations (De Singly, 2000) Although the concepts have been explored by a range of disciplinary perspectives, sociology and psychology have been the principal actors in addressing them, most often as a transitional period from childhood to adulthood (Galland, 2001). From a

psychological perspective, researchers have commonly theorized young adulthood following Arnett's (2000) research on 'emerging adulthood'. This period, typically referring to ages 18-25, is characterized by individual markers (such as maturity, autonomous decision-making or financial independence), self-exploration and individualistic identity construction which determine the transition to adulthood. Several critiques of this model have emerged over the years, notably for its inability to consider the structural dimensions of social life such as gender, ethnicity, social class as well as the structure of labour and housing markets and social policy (Molgat, 2007). Alternatively, sociological perspectives have explored the underlying social structures that influence youth identity, as opposed to strictly considering individual and psychological factors. Galland (1991) defined the youth period on the basis of three particular transitions: residential transitions (i.e. leaving home), professional transitions (from school to work or having a 'real job') and relationship transitions (from being single to forming a couple and a family). Molgat (2007) has pointed to an integrative perspective of the passage to adulthood that considers both individual markers *and* transition markers but also the socio-economic structures that are constantly changing (i.e. labour and housing markets, economic change, social policies, etc.). Additionally, much research has focused on examining young adults' perceptions of adulthood to better understand how young adults conceptualize and perceive themselves. In Canada, although there is recognition of the complex and 'non-linear' transitions to adulthood (Biggart and Walter, 2006), it is not uncommon for this period to be described strictly in terms of psychological markers that consider individual maturation and responsibility as the key dimensions to attain adulthood (ibid).

These varied theoretical approaches have led to a complex and socially constructed understanding of young adulthood that sheds light on a period marked by heavy cultural expectations that have the potential to become very disabling for young people. Molgat (2011) points to different life trajectories that can significantly influence the transition to adulthood among young mothers, young people with no post-secondary diploma and young adults diagnosed with a mental illness. According to Molgat (2011), we have to consider other life trajectories that may fall outside the 'new norms' of the transition of adulthood (e.g. prolonged studies, increased support from support from parents, etc.) and focus on what Coté (2006) considers the 'forgotten half' (Molgat, 2011:38). This term refers to disadvantaged young people with fewer opportunities such as ethnic minorities and immigrants, people with disabilities and marginalized people. While not referring directly to young adults with chronic health conditions, it seems appropriate to

consider how social inequalities, challenges and difficulties and several other factors can influence the transition to adulthood. It would be appropriate to consider the extent to which young adults with chronic health conditions are faced with challenges and the effect it may have on the transition to adulthood.

For the purpose of this research, the concept ‘young adult’ has been used for two reasons: first, as a way to highlight and recognize the various forms of pressure young people with chronic and disabling conditions experience as a result of cultural and societal expectations linked specifically to attaining adulthood; and second, because of the concept’s high prevalence and common usage within research and society in general. While participants were recruited on the basis of age (18-35) The interview guide was also structured with specific questions that addressed how young people defined themselves as young adults, young persons or as a complex mix of these identities.

1.5.2 Young adults with chronic illness

Research on the experience of chronic illness within young adults is limited and has been largely focused on understanding ‘disease’ specific aspects (many studies conducted on specific diseases such as diabetes, cancer, fibromyalgia, etc) (MacDermott, 2014). Research has also been conducted from a wide range of disciplines (i.e. psychology, sociology, nursing, education, anthropology), but have largely focused on two specific components: the impact of chronic illness on young adults’ identities as well as on adolescents’ transitions to adult healthcare. This section will elaborate on both topics to offer a better understanding of how the experiences of young people have been framed.

Research on emerging adulthood and the transition from adolescence to adulthood has focused on understanding it as a tumultuous experience (Arnett, 2000; Dornbusch, 2000; Goldscheider & Goldscheider, 1999), but it has also been argued that having a chronic health condition may further complicate this transition (Blum et al., 1993). The literature related to this transition often utilizes a life-stage approach to human development (Palmer and Boisen, 2002) and considers the complications that arrive in the developmental transition from adolescence to adulthood (ibid). Referring to Arnett’s (2000) model of emerging adulthood, there is typically greater interest in the challenges illness can pose in achieving independence and self-reliance (Palmer and Boisen, 2002). In their research, Palmer and Boisen (2002) studied young people aged 20-28 with Cystic Fibrosis to determine the psychosocial impact of disease on their lives and

highlighted major themes: independence and normalization, stress, coping and resiliency as well as responsibilities, successful transition and goals for the future. Impacts of the disease on young adults are essentially related to financial obligations and the costs of healthcare and health insurance.

Berntsson et al. (2006) studied the transition to adult health care for adolescents with long-term illness and concluded that a young person's well-being heavily relies on their ability to make decisions about their treatment, their lifestyle and to take their own responsibility. This was considered an important factor for personal growth as well as for the successful transition towards adult care. This increased their capacity to manage their own illness (for example, having knowledge of their own body's needs and reactions) and was considered an essential strategy to cope with stressors caused by the illness (Berntsson et al., 2006).

Other studies have focused on the culturally constructed concept of emerging adulthood as an important period of identity development, especially because there are many important transitions during this period of life such completion of studies, a move of residential location, new relationships, etc. (Shanaham et al., 2005). These periods of transition often imply a set of different behaviours such as increased responsibility, independence, autonomy and maturity (ibid). More particularly in the instance of illness and disability, several authors have demonstrated the possible disruptions of chronic illness on young adults' lives. Charmaz (1987) and Bury (1982) speak of 'biographical disruption' which refers to the biographical timing of illness which influences the "extent of its defined disruptiveness" (Charmaz, 2010: 18). In this sense, young and middle-aged adults often find that their chronic illness 'disrupts' their life path, plans or even identity and requires them to reorganize "taken-for-granted structures of everyday life" (Monaghan & Gabe, 2015: 1237). This concept has been critiqued, mostly by postmodern and disability scholars who state that the concept does not apply to children diagnosed with chronic illness at infancy or at a very young age as their condition has likely always been a part of their identity (ibid). For some, chronic illness could be more of a "biographical continuity" than a "disruption" (Monaghan & Gabe, 2015 : 1249). Furthermore, the authors argue that biographical disruption is merely a concept that reproduces 'healthist' culture. "In particular, its emphasis on micro-sociological meanings in a healthist culture might lead researchers and policymakers to neglect the wider, structured nature of society as a network of relations that are irreducible to individual behaviour and which pattern ill-health" (Monaghan & Gabe, 2015: 1249). Nonetheless, much

research on young adults with chronic illness has viewed the experience as disruptive and often theorized it as a biographical disruption.

The concept of ‘normalizing’ or ‘passing’ for normal, especially for young adults has also been a largely discussed topic within academia. “Normalizing is a process in which the person treats a symptom, disability or accommodation to illness as routine. It is a way of managing appearances and views of self as well as a strategy for managing life with illness” (Charmaz, 2010:22). This also refers to identity disruption and is often defined as a way to minimize the effects of illness, especially when adults feel a certain pressure to conform to various societal pressures, demonstrating that they are capable of ‘passing’ as normal adults.

CHAPTER 2: CRITICAL DISABILITY THEORY AND THE PHENOMENOLOGY OF IMPAIRMENT

“The disease is not the problem; living is the problem.” (Wendell, 1996 : 5)

It seems almost inevitable when imagining a person with a disability to conjure up images of the middle-aged man in a wheelchair, the older woman with a cane or the visually impaired person with a guide dog. Without dismissing such disabilities, it is apparent that these conceptions do not represent the diversity of disabled experiences in contemporary Western society (or the diversity of disability transnationally) (Gorman, 2013). On the contrary, they point to the dominant medical model of disability which views it largely as a functional limitation, a personal tragedy and a loss of capacities that are often visible (Puar, 2017). Unfortunately, this conception of disability still prevails and has been labelled by critical disability studies activists as the ‘medical model of disability’, which considers disability as an individual deficit or a pathology that requires professional intervention (Kim, 2017). As a response to this limited model of disability, alternative frameworks have emerged over the last decades from various fields of study in the humanities and social sciences as a way to highlight the social, political and cultural factors in the development of the category of disability (Meekosha and Shuttleworth, 2009). Social constructionist analysis of disability and chronic illness, critical disability theory as well as the phenomenology of impairment are three frameworks that have rethought conventional definitions of disability to provide more inclusive understandings and practical ways to include disabled experiences within research and academia. The following section will explore the value of considering chronic illness and disabling conditions within critical disability studies as well as the limits of the self-management approach to address chronic illness

2.1 Social constructionist analysis of disability and chronic illness

Social constructionist analyses of disability, also referred to as the ‘social model of disability’, emerged in the 1970’s in Britain to demonstrate how institutions and societies are, to a large extent, responsible for individuals’ disabilities, isolation and exclusion in society (Shakespeare, 2010). The model has been recognized for its ability to demonstrate the common social oppressions disabled people often share such as exploitation, discrimination and inaccessibility (ibid). According to Wendell (1996b), it is the various aspects of social oppression such as verbal, medical and physical abuse, job discrimination, inaccessibility of buildings and social isolation due to prejudice that people with disabilities are likely to have in common. For example, societies’ ‘normal’ or ‘standard’ pace of life can be extremely disabling for people with disabilities. The

expectations of performance and work, the pressure to work fast and efficiently, to work on a full-time basis or to continuously be a 'productive' member of society are some examples of how societies expectations can be quite disabling. One could imagine how the failure to live up to such extensive expectations can result in tremendous feelings of guilt, inadequacy and hopelessness. More particularly, young adults with chronic and disabling conditions are at risk of experiencing additional stresses as they both have to cope with society's 'general' expectations but also the expectations tied to the transition to adulthood. Similarly, Wendell (1996b) argues that societies that are both physically constructed and socially organized with the "unacknowledged assumption that everyone is healthy, non-disabled, young but adult, shaped according to cultural ideals, and, often, male, create a great deal of disability through sheer neglect of what most people need in order to participate fully in them." (Wendell, 1996b :39). With these considerations, it becomes increasingly clear that there is more to disability than the historically privileged biomedical understanding. Additionally, disability scholars have pointed to the social models' effectiveness in building a collective sense of identity among disabled people as well as improving self-esteem on an individual level by stating that society at large that should be held responsible rather than the disabled individuals (Crow, 1996; Shakespeare, 2010; Kafer, 2013).

The social model has also received criticism, largely for its inability to consider impairment as part of many disabled people's lived accounts of disability (Crow, 1996; Wendell, 1996b; Shakespeare, 2010). Crow, for example, states that "The social model works well on a large scale - it is succeeding in tackling discriminatory social structures and demonstrating our need for civil rights legislation. Where it currently lets us down is at the personal level - its capacity to include and represent fully the range of disabled individuals." (Crow, 1996: 2) By focusing on societal levels of oppression and discrimination, the approach has neglected to prioritize individuals' experiences of their own impairment. By silencing these personal experiences, it completely dismissed both difficulties resulting from impairment and the positive aspects of impairment such as the development of certain skills or abilities. It has also been criticized for separating disability and impairment as if they were separate entities when in fact, they are difficult to separate in everyday life. Although the social model seems to be indispensable to most disability theorists, it seems important to consider how impairment is a crucial component of disability experience, especially within chronic illness. The next section will explore how chronic illness can be considered as disabilities through a "renewed model of disability".

2.2 A renewed model of disability, bringing back impairment

Susan Wendell (1996, 2001), a self-identified disabled woman, speaks of her personal experience with chronic illness in her book *The Rejected Body* as well as in her article *Unhealthy Disabled: Treating Illnesses as Disabilities*. Wendell clearly distinguishes between disability and chronic illness, as well as the potential dangers of doing so. According to Wendell (2001), it is important to distinguish between ‘healthy’ and ‘unhealthy’ disabled, the former referring mostly to someone whose physical conditions or limitations are relatively stable and predictable (i.e. people who were born with disabilities or people who do not need much more medical attention than other ‘healthy people’) whereas unhealthy disabled refers to individuals who might be motivated to seek medical treatment for the onset of their conditions (i.e. people who are chronically ill (acute and/or chronic)). She adds that both categories remain in flux but that individuals with chronic illness may face similar conditions and limitations as a healthy disabled person although they might be clearly or obviously disabled to others. However, this can be particularly challenging because people who are chronically ill are likely to have trouble getting recognition of their illness and constantly having to justify or prove their conditions to others (Wendell, 2001).

Although their perspectives go back several years, both Wendell (1996, 2001) and Crow (1996) propose ways to understand disability which is still relevant today. According to Crow (1996), impairments often takes the form of pain, fatigue, dizziness, nausea, depression and are far from strictly being medically based descriptions of bodies or minds but represent ways these impact everyday activities and experiences over time. The typical societal response to impairment has been to treat impairment as a medically defined condition of a person’s body or mind. But, as they argue, we need to consider the phenomenology of impairment, that is exploring how people “experience, live with, and think about their own impairments,” which could contribute to, “an appreciation of disability as a valuable difference from the medical norms of body and mind” (Wendell, 2001: 165).

2.3 Critical Disability Theory and Phenomenology of Impairment

As previously stated, scholars have turned to disability studies to consider both disability and impairment to heighten awareness on disability matters and develop appropriate services and make more sense of the oppressions that are lived on a daily. Critical Disability Studies (CDS) has emerged both as an area of academic research and professional education in the western world in

the 1970s and has continued to expand in the 21st century (Meekosha and Shuttleworth, 2009). It has emerged notably to re-evaluate critically past work in disability studies that largely focused on the social model of disability and is considered as a move away from the preoccupation with binary understandings (ibid). Within CDS, there are numerous theoretical standpoints that have emerged such as feminist theories, Marxist and political economy perspectives and critiques of the discourse of normalcy that have employed principles and ideas from a range of current critical social theories (Hiranandani, 2005 ; Meekosha and Shuttleworth, 2009). For the purpose of this study, we will focus on Tobin Siebers (2011) Disability Theory as well as Hughes and Paterson (1997) phenomenology of impairment.

Tobin Siebers was considered a “champion of disability studies” as he contributed to the development of the discipline of disability studies, notably through his book *Disability Theory*. In his book, Siebers shares perspectives similar to other disability scholars concerning the limits of strict social constructionist perspectives of disability as well as the limits of post-structuralist theories that largely consider experience as a linguistic construct rather than an embodied experience. The author proposes many strategies to redefine disability, notably through “complex embodiment” which refer to the effects of impairment (e.g. chronic illness, pain or the rather physical components of suffering) that accompany disability (Siebers, 2011: 25). His main argument is that current academic discourses produce the illness it seeks to cure by dismissing the body as well as the diversity of lived experiences within people with disabilities. Siebers also offers critiques of identity politics that are pervasive within disability studies as well as the humanities, for being centred on ‘able-bodiedness’ and ‘able-bodied’ standards of identity that are very normative.

Paterson (2001) and Hughes and Paterson (1997) suggest a “phenomenological concept of embodiment” which provides conceptual tools to trace the ways in which oppression and discrimination become embodied and ‘lived’ through everyday reality” (Hughes and Paterson 1997 : 82). According to the authors, this would allow researchers to understand the body as a cultural phenomenon rather than strictly a biological entity (Paterson, 2011 : 600). They also argue that much work with regards to disabled people talking about their bodies has been done through interactionist perspectives: “Such approaches have been criticized for offering mere descriptions of the discrimination faced by disabled people, rather than examining the conditions which produce their experience of oppression” (Paterson, 2011: 600). The author's main argument is that

impairment is more than a medical issue, “it is both an experience and a discursive construction” (Hughes and Paterson, 1997:329). It is a social construct, just as disability is considered a social construct within the social model of disability. As a result, the authors argue that the social model of disability cannot be considered an emancipatory approach for the disability movement, mostly because it is dualistic and neglects important aspects of identity and self-identification. Identity should be something complex, shaped by our experiences and the meaning we attribute to them. They suggest post-structuralism and phenomenology as two perspectives that can help us move away from a dualistic approach. Phenomenology will be used for this research because it provides the ability to analyze how lived oppressions affect young adults’ experiences of impairment (e.g. pain, fatigue, emotions, etc.). Essentially, since impairment is an important part of the illness experience, phenomenology will ensure these experiences are considered in the data analysis and give a better understanding of how certain dynamics influence experiences of impairment (e.g. how certain experiences or interactions aggravate or minimize impairment).

CHAPTER 3: METHODOLOGY

This research project aims to understand how young adults with chronic illness experience their illness and the meaning they attribute to their experiences. As stated previously, the typical societal response to chronic illness has been to treat illness as medically defined conditions that rely on an individual's ability to self-manage. Additionally, studies pertaining to this have resulted in a specific interest in the aging population which has largely dismissed young adults' experiences. By considering alternative ways of thinking about chronic illness, notably through a social constructionist analysis of disability and the phenomenology of impairment, it is evident that there is a strong need to explore young adults' experiences of chronic illness. Consequently, semi-directed interviews were privileged to answer the following research question: How do young adults with chronic illness experience their illness and what meaning do they attribute to their experiences?

This research has four main objectives. Firstly, I would like to describe how young adults with chronic illness perceive their relationships and their social environment. Secondly, I would like to identify and describe the specific challenges and oppressions experienced by young adults with chronic illness. Thirdly, I would like to identify the strategies developed by young adults to cope with social expectations. Finally, I would like to explore how young adults with chronic illness perceive some of their experiences as positive. Finally, I would like to propose implications for social work practice and suggest appropriate intervention methods.

3.1 Data collection technique

The chosen data collection technique was the semi-directed interview as it is commonly used within qualitative research. This qualitative data collection technique consists of a 'minimally structured' interview where a set of questions is developed in advance by the interviewer which will be guided by the interviewee's rhythm (Padgett, 2017). According to Savoie-Zajc (2009), there are four main objectives of semi-directed interviews. First, this method of data collection is often used to *better understand* the experience, knowledge or expertise of the person being interviewed. Second, it seeks to make explicit the interviewees personal experiences with respect to a particular phenomenon. It also gives the opportunity for the interviewer to *learn* about the interviewee's thoughts, perspectives and behaviours in order to better understand their experiences. Finally, the process can be *empowering* as it has the potential of helping develop awareness on certain issues or concepts. This method was particularly appropriate for this research

project because it allowed me to explore and better understand both the experiences and subjective interpretations of young adults affected by chronic health conditions as well as the meaning they attribute to their experiences (Van Campendhout & Quivy, 2011). For example, the interview guide was structured to situate chronic illness in the larger socio-economic context in order to consider the various and changing social structures that might affect young adults' experiences of their illnesses (see Interview guide - Annex 1). This method is also advantageous because it is highly adaptable, as will be explored in the next section. Research on chronic illness experience can benefit from such highly adaptable research methods. In addition, the semi-directed interview encourages authentic dialogue and an opportunity to establish trust between the interviewer and the participant as it requires a set of skills such as active listening, empathy, non-judgment, etc. to ensure the participant feels at ease to share personal information (Savoie-Zajc, 2009).

3.1.1. Interview structure

The length of semi-interviews is typically 60 to 90 minutes and anything shorter is usually considered too short as it does not allow enough time for the participants to reflect and elaborate on their experiences (Seidman, 2006). In this research, all the interviews lasted approximately 60 minutes although one lasted approximately 45 minutes and another one hour and 40 minutes. Novek and Wilkinson (2017) explore inclusive practices in qualitative research involving people with dementia. Although not directly related to the research topic, the authors propose useful strategies that seem applicable to individuals with chronic illness. Therefore, I applied the following suggestions while conducting interviews: avoided stigmatizing language, allowed participants to choose the time and location of the meetings and finally was aware of factors that affected communication and adapted the interview questions accordingly. First, rather than using specific terminology to describe an individual's condition or illness (such as disease-specific terminology) each interview started with an initial question that gave the participant the opportunity to identify the terminology they preferred using when referring to their condition. I gave participants the opportunity to choose the time, location and duration of the interview. By being conscious of the fluctuating and often debilitating nature of chronic illness, I provided participants the option of conducting multiple short interviews within their home or other familiar environment to them to maximize comfort (Novek & Wikinson, 2017). For example, one interview was conducted in the participant's home, three were done in environments familiar to the participant and three at the University of Ottawa. Several participants took breaks during the

interview and one interview ended early for personal reasons. This also helped develop trusting relationships and created a comfortable atmosphere that encouraged participants to share personal information and experiences. Most importantly, by being flexible, it helped the participants feel safe and not judged for any impairments they might have had. I also offered alternatives to the ‘standard’ sitting interviews, allowing participants to choose what format the interview would take (sitting, standing, walking, etc.). Although this approach is typically used to benefit the researcher or the research project (see Carpiano, 2009), it was also used in this case to ensure the participants’ well-being. Two participants preferred walking as opposed to sitting interviews but due to weather, only one was conducted while walking. All the interviews were recorded with an audio-recorder with each participant’s permission. This facilitated the interview transcription and data analysis.

3.2 Sampling methods and selection criteria

Through non-probability or purposeful sampling, participants that met these specific inclusion criteria were eligible to participate: 1) be aged 18-35; 2) have a chronic and or/episodic illness not expected to disappear in the near future 2) have tried self-management strategies to manage their chronic illness and would like to talk about them (for ex: managing anxiety, trying relaxation techniques, meditation, etc.); and 3) feels comfortable communicating in French or English).

3.2.2 Number of participants

The number of participants interviewed is typically determined on the basis of sufficiency and saturation (Seidman, 2006). Due to practical exigencies such as time, the number of participants was limited to seven. This allowed us to obtain enough data for a masters level research project. Individuals were selected on a first come/first-served basis and no individuals had to be informed that they had not been chosen to participate.

3.3 Recruitment

Recruitment was conducted within a peer-led support group relevant to the study in the Ottawa region. This group was chosen to gain better representativeness and maximum variation among respondents who had both been involved in self-management programs and others who were not as involved. As the support group was open to all, it gave the opportunity to reach participants with various experiences. Some were actively engaged in health-care settings (e.g. self-management programs in hospital settings) while others were less engaged with medical settings and/or self-management programs. Conrad (1990) points to the importance of obtaining

respondents from non-medical settings as they may not be eligible for hospital-based self-management programs, may not be aware of similar programs or may have never obtained referrals to participate. When respondents are obtained from a medical setting, it implies that the participants already have connections to the medical setting, which might cause the researcher to miss people with certain chronic conditions that are not highly medicalized or who simply manage their conditions outside of medicalized settings (Conrad, 1990). We contacted the group organizer to get approval to post the recruitment poster on the Facebook group and attended a drop-in meeting to distribute the same posters. The people interested in participating in the study who met the inclusion criteria contacted me via Facebook messenger. A brief phone conversation was arranged to verify the inclusion criteria, offer different interview options and arrange for the interview to take place. At this time, I also explained the purpose of the study and emphasized the voluntary aspect of participation.

3.4 Data Analysis

The data collected was analyzed following a thematic analysis, which has two major functions: classifying and regrouping common themes and organizing them in respective categories (Padgett, 2017). This process allowed me to identify commonalities and the essence of lived experiences (Padgett, 2017). This method also allowed me to establish links between themes to determine if they overlapped, complemented or contradicted each other (Paillé & Mucchielli, 2012). Thematic analysis is relevant for this study because of the chosen methodology (semi-structured interviews) which draws on participants' experiences to create common themes. Inductive analysis was prioritized which means that themes and categories emerged from the data rather than being predetermined by the researcher. Themes were therefore identified after reading each verbatim transcript several times and identifying commonalities in the participants' discourses. Additionally, each theme was colour coded and relevant passages were inserted in a table organized according to five general themes and nine sub-themes. The first theme is relationships and social environment with the sub-themes of social recognition and relationships and exclusion (see Table 1). The second theme addresses the challenges and experiences of oppression and discrimination with sub-themes related to the issues of discrimination from the health-care system and social expectations of young adults. The third theme deals with coping strategies with the sub-theme of individual responsibility. The fourth theme encompasses the positive aspects of living

with a chronic illness and the sub-themes are understanding and resilience. The final theme identifies implications for social work practice through the sub-themes of empathy and support groups / community support. The table below represents the 5 themes and 9 sub-themes.

Table 1. Themes emerging from the interviews

	1	2	3	4	5
THEMES	Relationships and social environment	Challenges and experiences of oppression and discrimination	Coping strategies	Positive aspects of living with chronic illness	Implications for social work practice
Sub-theme 1	Social recognition	Discrimination in the health-care system	Individual responsibility	Understanding	Empathy
Sub-theme 2	Relationships and social rejection	Social expectations of young adults		Resilience	Support groups and community support

3.5 Ethical considerations

Obtaining ethical and informed consent as well ensuring a balance within insider/outsider status were some of the main ethical concerns to consider throughout the research process.

The foreseeable risks and benefits of participation were addressed during the recruitment process, notably through ethical and informed consent. Each participant was required to sign a consent form describing the research purpose, the foreseeable risks and benefits of their participation, their right to ask questions at any stage of the research process, their right to withdraw at any time as well their right to preserve anonymity and confidentiality. Although these dimensions were outlined in the consent form, we discussed the implications of the study and ensured the implications were understood (that is, informed consent). Blodgett et al. (2005) speak of personalized and empathetic problem-solving strategies such as being in tune and sensitive to the participant's needs and concerns to ensure that they are met throughout the research process. To ensure that participants' needs were respected, we stated at the beginning that one could choose to withdraw from the study at any time, could end the interview early and/or choose not to answer any question. We also clarified that there would be no consequences to their withdrawal and that the project's success did not rely on their involvement.

Another ethical consideration worth mentioning is what James and Platzer (1999) describe as the *insider-outsider* status of the researcher. This refers to the importance of taking into consideration one's own motivations to conduct research with a group of which we are part. In my case, I consider myself to be a young adult with a chronic illness which places me as an 'insider'. This has both positive and negative implications. On one hand, I consider this stance to have helped me establish trust and credibility with participants as I was considered 'one of them', as a person that understands and has the potential to relate in some capacity. This was a strength throughout the data collection process as several participants mentioned having participated for this specific reason; they felt their voice would be heard and had confidence in how their experiences would be shared. I was also sensitive to the realities experienced by this specific population and felt that this had a positive impact on my relationships with the participants (creating trust and confidence, being understanding, having empathy, etc.). Participants also offered very practical and insightful suggestions for programs for young adults trusting that there could be potential and positive implications. On the other hand, this status as a researcher risks creating a 'blurred relationship' with participants and the researcher must have the ability to 'act ethically and professionally within every interaction' (Blodgett et al., 2005: paragraph 28). To counter this potential challenge, I only disclosed personal information when appropriate or relevant while ensuring that the interview process was an opportunity for the respondent to share their experiences rather than an opportunity for me to do so.

3.6 Some considerations on limitations of the study

There are some limits to consider for this project, notably as this is a masters research project and there are time and resource constraints. For this reason, the number of participants interviewed was limited to 7. It is important to note that the number of participants was not determined on the basis of sufficiency and saturation (Seidman, 2006). Because this project is focusing on participants' subjective experiences, the quality and quantity of the information collected by participants was prioritized over a higher number of participants. Thus, we were able to go more in depth with each interview and collect more personalized information per participant.

Another limit pertains to recruitment. One self-management program was identified in the Ottawa region for recruitment but unfortunately, we did not receive approval to distribute recruitment posters during their workshops due to confidentiality reasons. The person responsible for the self-management program stated that recruitment posters would be distributed during

upcoming workshops, however, we did not receive expressions of interest from workshop participants. This was not a major setback as we were still able to reach participants through the support group who had participated in self-management programs as well as others who had not been involved. In fact, this was the purpose of recruiting within both organizations. Recruitment was also limited to one support group as many organizations require additional consent or guidelines in order to conduct research with desired participants (e.g. Hospital).

Finally, a potential limit worth mentioning is my previous and personal involvement within various self-management and support groups, as well as my placement experience at the Ottawa Hospital. While recruiting at the support group drop-in meeting, I met several participants I had previously interacted with in various settings. These participants did not choose to participate in the study, but it seems pertinent to ask whether previous interactions and/or their knowledge of my previous affiliation with healthcare (or other) settings might have affected participation. Additionally, it is worth mentioning that participants were all aware of my status as a young adult with a chronic illness as I am part of the support group and have previously attended meetings. Although I did not hold any previous relationships with the participants that chose to participate, their knowledge of my ‘status’ as a young person with a chronic illness might have affected the information collected. For example, some participants might have assumed I was already aware of certain matters or situations and consequently, left out valuable information or experiences that deserve attention (Seidman, 2006). It is also important to note that my personal involvement within various support groups and programs might have had positive implications as I am sensitive to realities experienced by this specific population.

CHAPTER 4: ANALYSIS

This chapter analyses research results related to the experiences of young adults with chronic illness to better understand the meaning they attribute to these experiences. First, I will explore participant characteristics to contextualize the research. The five subsequent sections correspond to each of the research objectives. The first section aims to describe how young adults with chronic illness perceive their relationships and their social environment. The second section will describe the specific challenges and oppression experienced by young adults with chronic illness. I will then identify the strategies developed by young adults to cope with social expectations and explore how young adults with chronic illness perceive some of their experiences of chronic illness as positive. The final section, written as a separate chapter, will propose implications for social work practice and suggest appropriate intervention methods.

4.1. Profile of participants

Data was collected from the participants, all aged 18-35, who self-identified as having a chronic and/or episodic illness and who have tried self-management strategies to manage their condition (see Characteristics of participants - Annex 2). The sample includes seven women aged 20 (1), 26 (1), 27 (1), 33(2) and 35(2). Although medical diagnosis was not required to participate, the following conditions were disclosed: Immune thrombocytopenia (ITP) and fibromyalgia (FM) (1), chronic migraines (1), undiagnosed chronic pain (1), spinal cord injury (1), cervical disc bulge and annular tear (1), nerve pain (1) and spinal cord condition (1). Additionally, employment was not a criteria for inclusion but was identified by participants as central in their experience of chronic illness. The occupations disclosed were the following: student (1), unemployed (1), front desk assistant at a hotel (1), librarian (1), federal public service employee (on long-term disability, LTD) (1), support analyst at a hospital (1) and health-care professional (on LTD).

Participants were asked which words they would like to use when referring to their chronic conditions. Many terms were identified: *“injury”*, *“disability”*, *“pain”*, *“chronic pain”*, *“illness”*, *“chronic illness”* and *“condition”*. Interestingly, the term *disease* was only used by one participant when referring to the diagnosis of *“lyme disease”* but the majority of participants either referred to specific medical conditions when referring to their condition (e.g. fibromyalgia, chronic migraines) or specific events (i.e. spinal cord injury, traumatic event) that brought on their condition. One participant stated not having a diagnosis but referred to her condition as chronic pain. As mentioned in the first chapter, this confirms the significance of considering other

dimensions of illness and disability that might not be rooted in the historical medical conceptions of disease.

4.2 Relationships and social environment

4.2.1 Social recognition

Participants were asked how their social environment reacted when they were both in seemingly good health and not doing well. When they seemed to be doing well or having a good day, respondents stated that their friends and family were “a lot more happy and supportive”, “very confused”, “taken aback”, “cautious” “acting normal”, and commented “oh you're getting better?”. When not doing well, respondents stated that their social circle would “get annoyed”, “react with anger”, “think that I am overdramatic”, “not know how to react”, “not very empathetic”, “try to be supportive”, “concerned”, be “very understanding”, “amazing”, and “great”. The variety of responses demonstrates general confusion and a lack of understanding of the implications of having a chronic condition at a young age. Respondents attributed this lack of understanding to three major factors: the invisible aspects of impairment, the fluctuating and changing nature of impairment and the implications of having a chronic condition at a young age. These factors were perceived as important to young adults because they impact their self-perception and the relationships they have chosen to maintain as a result.

All the respondents explained that the invisibility of their impairments such as fatigue, pain, depression and other mental health issues was a significant barrier to feeling understood by others.

[...] even if I'm in horrible pain, it's hard to describe what you're going through and it's hard to explain why you can't do certain things because they look at you and they think you're fine like that goes for friends and family. – Jada

I wish people would understand, yeah, your day to day you may look good, you may look fine, but inside you're not. The way I explain it, because my friends are like, “what does it feel like?”, I'm like “think about it, you know when you have the flu, and your body aches and you just feel like staying in bed and you feel like shit...it's like that”. - Priya

For Jade, having family, friends and her partner not understand the extent of her fatigue felt as though she was being judged or perceived negatively.

[...]like for me personally, my social life is affected (by my chronic illness) just because you know to get through the day, it's quite tiring sometimes and so it's just, you just don't have the energy to go out or interact with people [...] And so, you know, it's perceived as me just you know, being lazy or just wanting to sleep in instead of getting up and doing things versus what I'm actually struggling with. I'm lucky I have a very

understanding boyfriend, but it does create challenges sometimes when you know, he wants to be able to do something and I just don't have the energy. – Jade

Judgments can also be felt through others' comments which, in turn, makes young adults have to explain, justify and educate others about their impairments (Kattari et al., 2018).

It's invisible to most people so, I'll meet a new person and they may never even know but this is what I deal with on a daily basis. Kind of like my coworker said, she's like, "oh, you know, like when I'm having a crap day, I don't look this put together". And so yeah definitely having to explain to people what you're dealing with, how it affects you. -Eva

The fluctuating nature of chronic illness has proven to be another important factor in determining whether young adults felt understood or not by people in their social environment. *"It's kind of like (my friends) they're like, "oh you're feeling better? Like, oh you're getting better." You're like no, no you don't understand chronic illnesses is up and down up, up and down... tomorrow I might be in bed, you know"* (Stella). For Sascha, it becomes a problem when she is perceived by others as 'healthy' and her impairments are not taken seriously.

[...] there is an assumption that old people have invisible illnesses whereas people don't make the same correlation between young people. I've had old ladies yell at me for not giving up my seat and stuff like that. Not even being, just like saying "Oh I have a condition I need to sit down". I even pull up my card and stuff and show them and they're like "I am an old lady so let me have that seat!". You want to give them your seat too because you know, they're an old lady and you're so sorry. But I will also fall because if stand up on a bus, I will crouch. -Sascha

In this case, it is both the invisible aspect of impairment that is not recognized and the expectation that a young person should not be ill or require specific accommodations typically afforded for the older population. Interestingly, two participants explained that there were also positive implications to the fluctuating nature of chronic illness; that is, when they were having a 'good pain day', they would get to "feel normal" and "live like other people are living". Some participants also explained that on good days, they would receive recognition and optimism because they resort back to their 'old self' and were more positive to be around "[...] they (my family) are a lot more happy and supportive and they say "well that's the old Mala!".

Another barrier to being understood often relates to being younger and that chronic illness is not expected to occur at that age. In addition to having difficulty getting recognition for their

invisible and fluctuating impairments, young adults explain having to justify their illness because they are at an age where illness is not expected.

I think it's a lot of you know, people don't expect it from a young adult. I think, you know, once you get older, people almost like they're more understanding about it, but when you're young they're just like "oh well I have back pain too" [...]...people will look at me till this day, a friend just said to me the other day, she said "oh my God", she goes, "If I could look like you on one of my shittiest days, I'd be happy!" and it's like, you know, I understand that like I might look fine, but I don't feel fine. -Priya

[...] people make jokes saying like "you're too young to be sick!" but (I would recommend) understanding and using language that's reflective of the fact that other people can have illnesses and problems and stuff like that isn't just old people or young people. - Sascha

According to Kattari et al. (2018), similar comments can be considered as “ableist microaggressions”, that is, everyday comments and behaviors that perpetuate inequalities and stereotypes. Telling someone they are too young to be sick or that they look good for being sick are examples of microaggressions that demonstrate people’s inability to understand the extent of young adults’ impairments and point to underlying assumptions that they are too young to be ‘sick’. Because their impairments are not always apparent, young adults explain that others make them feel like their impairments are not legitimate, as though they are “crazy”, “overdramatic” and even “*feel pity from others*”.

Most participants also identified receiving a medical diagnosis as a crucial factor that determined how people perceived their conditions. In most cases, a medical diagnosis serves as a sort of proof that legitimizes the impairments they are experiencing and having difficulty justifying. “...when I got the fibromyalgia diagnosis, that kind of solidified the ability to say “*I'm not feeling well*” instead of just being like “*oh like I'm not feeling well today... I don't know why*” (Sascha). In this sense, having a diagnosis is useful in the way that it justifies the condition to others and allows young adults to be taken more seriously. Although some explain that even with a diagnosis, chronic pain is not understood and accepted in the same way that other conditions are, which might still result in the lack of recognition.

It's not something like, you know, like a disease like cancer where there are very visible side effects of it. It's a disease that...the impact of it is very well understood by society. Chronic pain isn't like that and I think it's because chronic pain is so different for everyone so it's really a hard one. – Eva

Similarly, not having a diagnosis or medical explanation can result in the disbelief of others about young adults' conditions and consequently, their exclusion from friends and family : *they're not very supportive (my family) just because I don't think they take the time to try and understand what I'm going through because they can't see it and I don't have a diagnosis* (Jada). For Sacha, the diagnosis helped her get more recognition for her chronic illness, but she considers that her age is an additional factor preventing people from understanding the implications of having a chronic illness:

For the longest time for like several years, I had no idea what was responsible for it (my chronic pain) now, like I have partly an explanation, but the general explanation is just nerve damage and there's not a lot of young people walking around with nerve damage. And so it's hard for people to understand. - Sascha

According to Stella, having her illness recognized by her social environment is not only dependent on the above-mentioned factors but also relies on the person's level of empathy and their own personal bias:

It depends to who (I explain my symptoms to) so to my mom no, she understands because she sees me like cry day in and day out. To my ex, yes, he doesn't understand how debilitating it is. He just thinks that I should get over it, which is difficult. To my physician, yes, and no. He understands my pain is real but he also thinks that I need...or he also thinks that there's an underlying psychological aspect to it, which I agree and disagree with. My psychiatrist thinks it's all psychological which I disagree with. The general public, once I tell them, they kind of understand but I have to explicitly tell them because I look perfectly fine. So like to my friends in general, they understand what I've told them but I have to explicitly tell them if I'm having a good or bad day because they never know because I look always fine. So it kind of depends on the person in my life. -Stella

As a result, interpretations from friends and family on how the condition is managed can contribute to feeling misunderstood and consequently, feelings of doubt regarding the legitimacy of their conditions.

4.2.2 Relationships and social rejection

The struggle to have their chronic conditions recognized from their immediate social circle (friends, family, coworkers, health care professionals etc.) was described as an important factor in the quality and quantity of relationships maintained, as well as the type of support received. Most respondents reported experiencing social rejection as a result of unacceptable behavior from people in their social circle which often resulted in their social isolation. Lack of acceptance,

factors relating to age and social expectations were explained as the principal reasons why young adults were excluded from their social circle. Conversely, factors that ensured their inclusion were identified as a person's ability to listen and empathize, be accommodating, spend quality time with them and willingness to communicate. Additionally, participants insisted on the importance of connecting with people who were able to relate and understand the particularities of their situation.

A recurring theme among respondents was the experience of rejection from friends and family, often attributed to their social circles lack of understanding or acceptance:

[...]but the ones that are having a hard time with it (my disability), I chose to distance myself a bit more and the ones who are more supportive and understanding are the ones who I choose to hang out with and be with and same thing, find different friends who may be able to be in the same boat and understand you better – Mala

My family is more like, you know, "just suck it up buttercup". It's kind of the attitude that they have and so when I'm having a bad like chronic pain day, they're not the people I really go to for support. It's more so like it would be one of my close friends and I feel like maybe because they're my age or I don't know what it is, but they tend to be more understanding. -Eva

According to participants, a person's ability to accept and recognize the implications of chronic illness is a determining factor in relationships maintained and in the type of support one will seek out. According to Eva, due to a lack of acceptance and understanding from friends, she has become less tolerant and as result, has had to distance herself for others:

I lost several friends, but I think I'm better for it. So I'm less tolerant. So basically I had like these instances where friendships fell apart and I was okay with it. And so I actually saw a therapist because I was like something's wrong. It's like why am I dropping all these friends? And so through we realized that in my case, I had become less tolerant of bad behaviors... bad behaviors that I, you know, just accepted and shoved under the rug with friends before and then eventually I just didn't have the patience inside anymore to deal with bullshit and to deal with bad behavior from friends. - Eva

For two respondents, their withdrawal has been a result of their inability to 'keep up' with activities people of their age typically engage in and which activate their pain:

I find you know, people in my age group are really active. I guess it might depend on who your friends are. But even if it's just, you know, going out shopping or going out to a bar walking around downtown or any like sort of outdoor activities along with a lot of people are involved in, it's hard to keep up with people and so it's hard to therefore spend time with them. -Jada

For Stella, being unable to ‘keep up’ with other activities such as traveling and partying as well as her perception of not feeling that her presence is appreciated has resulted in her exclusion:

... most of my friends ditched me when I was dying because I'm not like...I mean when I was like 18 and 20, like... most of my friends were partying and traveling and you're not much fun when you're dying. And so socially, I don't have many friends now and the ones that I do have I can't really go out and enjoy my time with them because I'm always in pain and so I don't really want to go like I can't drink because my medication and I don't want to go out because I'm in pain all the time. -Stella

Conversely, when friends adapt activities and their activity level to be more accommodating, it can have the opposite effect and strengthen friendships, as explained by Priya:

I think even with my friends it's different because of the level of activities we used to do together now are more sedentary which changes some of the friendships you have but at the same time I'm grateful for what happened because you really see who are the friends that stick with you and those who don't, who don't care. You really see who's your tribe, so in that respect, it was good to know and to see that. -Priya

One respondent explained that pressures and expectations associated with the transition to adulthood have resulted in her social isolation as she finds it difficult to relate to certain life experiences. She prefers avoiding situations where she is confronted to these events:

I tend to avoid things that just make me more emotionally upset and that doesn't mean like any toxic relationships, I think it just means like you know, not going to social events where all my friends are married and have babies and you know, like I feel like I haven't gotten there and maybe this is part of it, so I tend to avoid them for my own mental health every once in a while. -Eva

In turn, some respondents considered they were “complaining” or “venting” and stated that they tried to minimize the number of people they shared their feelings with, from fear of being ‘overburdening’.

As a result of similar experiences, respondents developed a better understanding of what makes relationships meaningful, and what kind of support they value in relationships. Emotional support, flexibility, accommodation and communication were considered important factors in maintaining healthy relationships. For Eva, emotional support is the principal type of support she values from her friends *... so I would say emotional support is probably what I get (from my friends). [...] Yeah. I just need to vent about how I'm feeling physically how it's affecting me*

emotionally, you know, they'll just listen [...]. For others, having friends and family members who are accommodating and understanding of their condition makes relationships valuable:

For my co-workers, for example, if they know I'm sore, they try help me not to feel guilty. Like, "If you have to go home, go. Or if you need to go sit down in the back and take a break, we have this". I just, you know, go sit down for a little bit. For my friends, I'd say they're definitely (understanding), like if I really want to hang out but I just don't have the energy to go out to the bar tonight or whatever, they're flexible to go you know, just like at a pub and sit down instead or like "do you want me to come to your place and we can just hang out there?" So my friends are very flexible in that way .- Jada

For Victoria, support is not limited to emotional support but rather, she considers that support is also linked to spending time with her and offering extra help for things she has more difficulty accomplishing:

[...] you know, when someone is sick and they're like "Do you want some soup? Do you want me to bring some soup? That to me is extra (support). So regular support is like, okay, when we're together if I talk about something like they're still there for me. They, you know what I mean, they listen to whatever the du du dah, but I mean, they're not going to go out of their way to do something extra you know, like for example, they're not like, "oh I'm going to take half an afternoon off to spend some time with you because I know it's rough to be alone" or they're not going to like bring me a cooked meal and bring it to me like my mom would, you know what I mean? Like that's what I mean by extra. My best friend did all that and more so, you know. - Victoria

All of the respondents discussed the importance of developing friendships with people that have had similar experiences and illnesses or that have the ability to better understand or relate to some of the things they are going through. *"That was like the best thing for me support groups, like finding people that are like me... that like I'm not alone"* (Stella). Sharing experiences with people who can relate was identified as a beneficial way to get support but also to feel like young adults are helping others that might need support:

I became friends with two of the girls, young moms as well and they both had concussions so they were dealing a little bit differently with brain and cognitive difficulties but they were still dealing with disabilities. I found it was great to have their support as well and you know, now we're friends online and we reach out to one another still, so I found that support really helped. – Mala

Finally, effective communication with friends and partners was mentioned as an essential part of maintaining relationships, especially to make people understand the implications of having a chronic illness.

It's invisible illness like I was saying before, so I don't think they (my friends) actually understand the severity. I talked to my brother and he said he's like you're not super vocal about your pain all the time. [...] They should ask more questions and I should be more vocal, it's kind of like both our faults, you know? So yes, I think it's true that people don't realize unless you're super vocal about it or unless it's showing like that you have an injury and how bad it is. -Victoria

Several respondents discussed the importance of effective communication to educate others about their conditions. However, some participants explained not wanting the responsibility of having to “educate” or discuss their illness with others because they are not always heard, (especially in medical settings) and because of the effects of their impairments on their ability to do so (e.g tired and lack of energy to explain to others continuously) and by fear or being rejected or misunderstood.

4.3 Challenges and experiences of oppression and discrimination

4.3.1 Discrimination in the healthcare system

Every participant spoke to their experiences within the healthcare system which includes frustrations with the lack of care and proper treatment from the medical community and well as the struggle of having their illness recognized by health care professionals. These recurring topics bring to light specific discriminations related to age, which is for the most part, recognized by the participants themselves. For the following two respondents, the lack of treatment and care from health care professionals and not being taken seriously are important factors in the aggravation of their condition:

Unfortunately, I went into the hospital five times complaining about my back pain, leg pain and tingling and not able to walk well. This was before the surgery. This is a young adult coming in very physically active, who has said that she used to do tons of sports and “It's sciatic”, they told me, “dump the weight dump the weight”. I've been a heavy girl my whole life, I don't know if this is necessarily sciatic pain all of a sudden? I was definitely judged right away and I wasn't given an MRI and unfortunately that's what the big thing was... no MRI, the slipped disc got so bad that it was then crushing the spinal cord so bad that it made me paralyzed and that was the day that I called 911 and they called me an ambulance and they had to listen. I had my MRI and then they saw the slipped disc. There was a lot of judgment at the beginning, just to get the diagnosis and even now when I am disabled, walking with a walker... - Mala

I think that in the medical community it's like “you're young, you'll heal, you'll be fine”. You know, they have kind of like, “you're going to be okay.” They don't provide as much support not thinking that you need it and to be honest, the medical community has been shit to me...mostly! Like when I got hurt, I went to emergency before going

to the hospital and the doctor was literally like “Are you stressed? What's your job? Do you have a lot of stress in your life? And he's like, “yeah, it's probably caused by stress. It's probably why your neck hurts. I'll give you some relaxants” - Victoria

Having a condition that is not expected to occur at a young age can result in disbelief from healthcare professionals and the lack of proper treatment. *“I think the medical community, it's harder for younger people to talk about pain and to access pain management services because once again the expectation is; you're young, this should not be happening to you” (Priya).* Jada considers that her age is the main reason why she has hasn't received proper treatment, which has resulted in not having a diagnosis for her condition:

I don't want to say that as a young adult you're not believed. But I almost feel like for a while, it was like “oh well see if she grows out of it” or things like that and so there's kind of that. I feel like I almost spent a period of time waiting when they could have been investigating more just to see what would happen or things that improve so there was a lot of I think wasted time in terms of finding a treatment or even a diagnosis... - Jada

Lack of proper medical care is not only experienced initially for diagnosis but seems to be a recurring experience affecting young adults when seeking medical treatment in health-care settings. A lack of recognition from health-care professionals is also a common occurrence that reinforces the above-mentioned issue relating to young adults feeling their conditions aren't recognized and taken seriously.

I would say for doctors, I felt a lot of times like I've gone in not to see my regular doctor, but if I've had to go to emerge (emergency) and things like that. I feel like it's perceived that I'm just trying to get free drugs which is a horrible feeling just to feel like no one has even taken the time to look into things. I was in there maybe three months ago and they're like, oh, well, you have an MRI in five months. So, there's nothing we can do until then, but it was like well, I've been off work for three days like I can't sleep, I'm in extreme pain. My doctor can't fit me in and they didn't offer me anything. And that's happened on more than one occasion and it's like...it's an experience that I've heard from multiple people as well. So, I just feel like we do struggle for recognition. – Jada

The result of disengagement from the medical community has been experienced by many as a burden that increases personal responsibility for their own conditions, when in fact they are unable to take on this role by themselves. Scambler (2010) and Bury et al. (2005) refer to this as a period of disengagement from hospital-based treatment care that uses approaches encouraging individuals to control their illnesses. Victoria explains it this way:

I think too much is put on the person that's injured shoulders, you know, when there's already so much stress that they have to deal with. I think that there should be more accountability from the doctor's perspective...[...] you have to like I said do research, do the management, you have to do figure out if you're doing the right thing... like you don't know, you're not an expert. I'm not a medical expert. [...] a lot of research that I have to do, a lot stress is put on me and I feel like nobody else cares in the medical community. – Victoria

[...]when I first got injured, and I met a lot of incompetent doctors, it kind of made me realize even more how important it was (self-management) because I was like, well if I'm not doing it, nobody's doing it like you really are left kind of alone in this to be honest. Every doctor has a piece of the pie but nobody's baking it. – Victoria

Others, such as Stella, are stigmatized by healthcare professionals which prevents them from accessing further medical care:

When I go to the hospital to either be looked at like a huge junkie that just wants drugs or to find a compassionate doctor that's like “oh you're not crazy, you just want pain relief”. It's literally 50/50 if I get either or and I wish that more doctors were compassionate and didn't just see me like coming to the hospital often and went like, “oh you just want drugs” and to see me more as like, “oh she comes here often like she must be in a lot of pain”. So I like I've stopped going to be the emergency room because there's a note on my file that's literally “don't give her anything, she comes here too often” and I'm like, I go there often because I'm in a lot of pain often but yeah, it's... the system sucks. -Stella

Sascha feels similar pressure and has been reminded by others to exaggerate her symptoms in order to be taken more seriously by health-care professionals:

I think that a huge part of it is having people who believe you in the medical field. So often, it's like “are you sure you're not exaggerating that?”. There's another kind of weird issue with that, that in some cases you have to exaggerate your symptoms in order to be heard. So you know, when I go to the doctor I'm a generally very happy and bubbly person you know, but when I go to the doctor my mom would be like “you're too happy! You can't be happy right now or else they won't see you as that (sick).” Or I won't wear makeup on days where I go to the doctor or I'll wear like shabby clothes not to make them think that I'm worse than I am but to make them believe that I am as bad as I am you know, yeah. -Sascha

Kattari et al. (2018) speak of “ableist body policing experiences” to refer to ways people in our social environment express disbelief in the conditions they do not understand which, in turn, forces individuals with chronic illness to prove to others that their conditions and/or symptoms are real and have to advocate for themselves. The experience of the participants in this respect is so repetitive that it suggests that such discriminatory practices are pervasive in health-care settings. This serves to maintain and encourage normative constructions of *ableism*. This type of oppression

can result in young adults internalizing the oppression they experience, and manifests itself through frustration, shame, doubt about their own abilities and the pressure to conform (ibid). The following section examines other types of discrimination and oppression experienced, and at times internalized, as a result of social expectations related to age.

4.2.2 Social expectations of young adults

In addition to the traditional expectations of young adults (e.g. achieving independence, entering permanent couple relationships or getting stable employment), young adults with chronic conditions explained experiencing additional pressures. Most respondents reported feeling pressure to conform to various social expectations as a result of their young age : expectations to be ‘healthy’ and get ‘better’, to be a productive member of society, to ‘have fun’ and enjoy life and to work towards getting back to their “*old self*” as well to as aspire to live a ‘normal’ life involving work and/or getting back to work. These forms of pressure shed light on the heavy cultural expectations that are linked to the transition to adulthood but point to the specific challenges that make transition to adulthood more difficult for young adults with chronic illness.

Several respondents described their experiences of discrimination as a result of everyday interactions with people in their social environment. The expectation that they will get better or that they will be ‘fine’, is felt through other people’s comments. Priya explains : “*when you have a chronic illness it's kind of like at the beginning, they're like, “oh my God, you're hurt!” and that's like a normal thing in life, people get hurt sometimes but then...it's “get better”*”. According to Victoria, “*I'm in so much pain but like it's just yeah, it's because I'm young they're like, “oh like you're fine.”*” This social expectation that a young person will recover from illness represents underlying societal conceptions that consider illness as a temporary personal ailment that can either be cured or better managed. In this sense, young people explain feeling the pressure of being healthy or working towards achieving health.

According to Eva, she felt expectations from her workplace after getting injured:

So at the time (of my accident) work wasn't understanding of it, you know, it happened on a Wednesday afternoon and on Friday they were wondering when I was going to come back to work. So I felt that pressure and you know, I think if I had been older that pressure wouldn't have been there. I think they're like, “oh she's 25, you just got knocked around by car, shell be fine.” But as people get older, they don't bounce back as much. I think there's more understanding of it as you get older. – Eva

The social pressure to recover quickly at a young age and return to work as quickly as possible is clearly stated by Eva and Priya, as they felt they needed to return to work right away to continue performing and maintain what is socially expected from them:

[...] but I think like it (my injury) happened to me when I was 25 and I was literally like, I was in a training program at work for a really like fast-track, high-level job. And so, three days after my accident, I was back at work. I had a bruised face, a wrist in a cast and my shoulders were burning and I still went to work. [...] it wasn't the smartest thing at the time but the problem is that when you're at that stage in your career where like if I don't do this, it's going to affect me and like my whole career path for the rest of my life. You just like, you just power through it. – Eva

At work because after my first surgery and first hospitalization, I sorta was in denial thinking it was a rare condition you know, I'm young and I'm going to recover, and things are ok. So I went back to work pretty fast like after 8 weeks which is rare but I wanted to prove to everybody and myself that I could do it. – Priya

Other respondents referred to how their illness disrupted important life events associated with the transition to adulthood such as entering a relationship, parenthood and completing school:

So, I think when you're a young adult you had those extra pressures that were just trying to like set up the rest of your life, right? I definitely didn't date at all for like five or six years after my accident. I always felt like shit to be honest, you know, like you don't feel like you're worthy of dating someone, you don't feel like you have anything to offer. [...] Like dating was really hard because people will be like well, like, you know, how do you meet someone and explain to them what you're going through? I think that's what kind of kept me out of dating. -Eva

I feel like a lot of the learning and growing that I was supposed to do as an individual got stunted by me having to deal with the chronic illness so I don't feel as though I have done the developing that an adult of 26 years should have done by now. Like if I hadn't gotten chronically sick, I wouldn't... I would have my master's by now. I would have still moved in with my boyfriend, we would probably have a house and I would be ready to have a kid in like a year or two. Now, I'm just starting my master's, we're... like I'm going to move in this weekend. But like we won't [...] he's going to start his master's at the same time as me, we won't be ready for kids before like three or four years like everything is shifted by three or four years. - Stella

According to Charmaz (2010), the 'biographical timing' of the illness can disrupt life paths and plans, as stated by both participants. They also feel personal responsibility and frustration in relation to their 'inability' to conform to *ableist* expectations of society which translates into 'internalized oppression' (Kattari et al., 2018).

Additionally, this pressure to conform might lead others to minimize their illness or ‘pass for normal’ in order to fit in with the expectations of a ‘normal’ adult:

I didn't want to disclose the fact that I had something going on because I like the idea of living normally. So I didn't tell them (work) at first they would see me waiting at the bottom for the elevator and they would walk by and my managers would be like “Why are you waiting for the elevator?”, and things like that but once I became more open and I learned more about being comfortable with it, they were a lot more understanding and I didn't really have any kind of issues apart from just like I just felt like a pain. – Sascha

In this case, even when Sascha’s workplace was understanding and accommodating of her illness, she struggled with feelings of guilt for requiring accommodations. Interestingly, many participants explained that their workplace was generally accommodating but that they still felt the pressure to perform and be productive like others.

Other respondents felt the pressure from peers, family, coworkers and other adults to be having fun and doing activities that young adults typically engage in: *“I definitely think as a young adult you’re kind of placed into a group of you know, you should be out having fun and should be doing this and you shouldn't be like dealing with this sort of thing”*(Jada). For some, this meant feeling guilty for not being able to keep up with activities typically associated with that age or withdrawing from social situations.

Finally, some participants struggled with unanswered questions and uncertainty about the status of their condition and with the stress of not knowing whether they will be able to keep up and fulfill the roles linked specifically to adulthood:

[...] when we're young and we have chronic injuries, we don't know how it's going to affect us for the like the rest of our lives and we're worried because we're like what if this gets worse? Like... I'm 33. Okay. Hopefully I have 50 plus years to live. Like that's a long time to have a chronic injury. Like is it gonna get worse? – Victoria

[...] what if this happened when I was seventy? I would be retired, probably would not be as active anyway, I would probably be like travelling the world on some cruise where everything's taken care of for you. But younger you still have your roles that you need to fulfill. You need to work because if you don't work you don't have a financial stability, you can't raise your kids. Look, I'm a firm believer of “give them an advantage”. You still have to take care of your house, your home, all that. I'm not ready to downsize to an apartment, like no way a condo, my kids are still young they need that. -Priya

In sum, it is clear young adults with chronic conditions are faced with challenges and expectations that are unique to the period in their life. Respondents have stated that these pressures have led them to manage accordingly, to take on more responsibility, to try to minimize the effects of illness, to cope with feelings of guilt and to acquire endurance.

4.4 Coping strategies

4.4.1 Individual responsibility

When participants were asked if they considered themselves as the most responsible person for taking care of their health and if they considered self-management skills essential to manage their condition, all responded affirmatively. Participants explained that self-management practices helped reduce the severity of their impairments, allowed them to learn skills needed to cope with disability and chronic pain and empowered them to take control of their life. For most of the participants, the self-management skills they had developed were also as a result of the lack of engagement from health-care professionals, which in turn, made them the person most responsible for the management of their conditions.

Interviewer: When all is said and done, I am the person who is responsible for taking care of my health?

Yeah, I would say like I feel like I'm pretty much responsible for that whole situation. I would say you're responsible because you're the one that needs to reach out... whether it be initially or over and over again, if you're sitting at home struggling, no one's going to unless you call and make an appointment, you know, if I get referred to a doctor and I don't hear from them in four months, I'm the one who needs to call it. – Jada

I agree and like I said, there's nobody else that's going to do it for you... I don't think that's a bad thing though, but definitely at the end of the day, it's up to me to know like who I need to go see when I'm having this issue or that issue... it's up to me to put in the work to be able to like sit here for an hour. - Eva

[...] Until I took it upon myself, I was just complacent. I was just fighting against the pain. I feel like I was less empowered, I guess. I do think that at the end of the day, it does belong to me. I do think that other people have significant roles in that, so that your health practitioners have an important role and if they fail you, that really sucks. But that's the cool think too, like even if they fail you, I'm able to then go and find that route. - Sascha

These statements demonstrate that although the respondents are aware of the disengagement from the health-care system, some are empowered by having the responsibility of managing their own

conditions. Alternatively, Victoria expresses frustration with the lack of ownership from health-care professionals: *“Yes, but I don't think that's fair. I don't think that's right in a sense. Like I think that we have to take on too much responsibility. I think that there should be more accountability from the doctor's perspective”* (Victoria).

Self-management skills are explained by the majority as essential to manage impairment and pain which in turn, allows them to stay active and *“not letting the pain dictate my life”* (Priya). Two participants also attributed the improvement of their condition to personal success. According to Eva, her ability to self-manage is due to a personal skill and/ or a personal characteristic:

So I think that might just be like a personal characteristic that kind of helps me a lot (to self-manage) but I've talked to a few people and I see people struggling with that and so I think, if you don't naturally have that characteristic then yeah, it's harder for you to figure out “where do I go”? [...] At the end of the day, it's up to me to know like who I need to go see when I'm having this issue or that issue... it's up to me to put in the work to be able to like sit here for an hour. - Eva

The belief that their condition is dependent on personal success and their level of work and determination is also explained by other respondents, such as Victoria:

You don't understand... like I told you. I will try everything. I am like desperate, desperate, desperate. I'll try everything. You know what I mean? Like it's like I just want this to go away. I will do the work, you know, so I've like yeah, it's kind of a mixed bag too. Yeah like physio, swimming, like all of that you need to do by yourself. So I tried to do more meditation, but that's still to be worked on and it's hard to do when you have a mind that's like non-stop. – Victoria

This statement represents the dominant ideology that one needs to work in order to ‘get better’ or achieve an acceptable level of health. Three participants explained having goals to *“get better”* and get back to work or school, and others stated that self-management allowed them to work towards other goals such as maintaining a social life, friendships and participate in the community. Achieving these goals depended mostly on their ability to effectively self-manage or to find the right treatment to feel better and to continue functioning in society and having a good quality of life:

[...] so yeah and putting all these things (self-management strategies) into place so that you know, you can manage... like mindfulness or getting yourself into reading and doing all these things so that when you do get back into it (back to school), at least I'm going to have a basis, yeah. - Stella

Like a lot of the strategies like the pacing, energy conservation, meditation, muscular relaxation, identifying my negative thoughts and challenging them, that's been good. It helps me to take back the control that I lost. [...] Just to get to that quality of life that I feel I need to reach. Am I there to the point that I need to be? No, I'm not back at work. I'm not sleeping right. But I'm almost there. I'm almost there. But am I able to do the things I want to do, the things that give meaning and purpose and who define me as a person? I'm getting there. -Priya

It (self-management) also gives me I think motivation. It's kind of like 'ups the spirit' when you have hope, it's kind of crazy. And it's sad in a way to say that, but it's true like when you think "oh, I'm going to try this, maybe it's going to help or maybe whatever and it's almost like a placebo pill that sounds like it might not, but maybe it does because you think it's gonna help, you know, like it's all about state of mind and maybe you'll finally find something that'll help. – Victoria

By considering themselves as the person most responsible for their condition, some respondents perceived themselves negatively, as it can be difficult to achieve what is socially expected. Stella attributes her lack of autonomy and independence to her illness but also to her difficulties with medication management, as she can no longer manage her medication independently.

I feel like I should be further along. So I feel that I think of myself as negatively in that sense because I feel like had I not been sick, I would be doing like XY and Z now. So now I'm like... well shit I have all these things to catch up on now. So I think of it negatively in that sense which, I know that I shouldn't because it's not necessarily my fault that I got sick, but it's my fault that I have this lack of autonomy and it's my fault that my mom has my pills. So yeah, so yeah, I think of myself negatively because of it. – Stella

This represents how an individual could feel that they are responsible for the state of their condition due to “poor” self-management skills, especially if certain goals were not attained. Finally, it is clear that young adults perceive self-management skills as essential to maintaining a good quality of life, which includes minimizing the effects of impairment and being active in society. Difficulty in managing can however be experienced as a personal failure or interpreted as a need to improve.

4.5 Positive aspects of living with chronic illness

When asked if there had been any positive outcomes of living with a chronic condition at a young age, six of the seven participants were able to clearly identify several positive aspects. There were also certain positive outcomes that weren't explicitly identified by participants but that were important to include. The responses can be classified in two categories: understanding and resilience.

4.5.1 Understanding

Participants stated having a better understanding of the implications and the reality of having a chronic condition, a better understanding of “*what real life is*” early in life and a better understanding of the overall functioning of the medical system. The importance of being empathetic and having a work/life balance were also mentioned. For the following two respondents, being able to empathize and relate to other people’s experiences and offer adequate support was described as a strength:

[...] you're having a high pain day and you just want to lay in your bed and not listen to music and just be in the dark and yell at me to leave? I get that you know, I have bad days and things like that. - Sascha

[...] I'm a co-chair so I co-run it and help facilitate things and help support other moms in the community in Gatineau and Ottawa who are young women who are moms with disabilities and you're not alone... I try to support them with even just a text and a message like “how's your day going?” because I know how it feels to have somebody message and just check in on you so I wanted to be there for somebody else and I've now tried to encourage others, you know...- Mala

Two participants mentioned that their conditions made them “*mature and grow up faster*” and be a “*strong, independent adult*”. These participants developed an understanding at an early age of the implications of life and consider themselves as “*more independent*” and “*stronger*” as a result.

Another participant mentioned that she no longer assumes people are ‘healthy’ but rather considers the possible impairments a person could have.

I don't look at people and assume that they're normal, you know. I go with the assumption huumm that I wonder if they have this pain or things like that? Especially in terms of the bus situation, I get super anxious on the bus when someone sits down my brain goes "hmm I wonder if someone has something and that's why they're choosing that seat" instead of letting that old person on... - Sascha

The same participant also explained she has gained a better understanding of the medical system to help herself better navigate it but also to help others:

It has made me realize our medical system and how that works, its flaws and its pros and that's like super helpful to know if down the line my parents get sick or if someone I know needs help navigating that and having an advocate for them during appointments or type things cuz I've seen people doing it for me... - Sascha

Finally, participants demonstrated a good understanding of certain concepts and situations that weren’t always easy to grasp. For example, all participants were able to understand and identify

discriminatory practices within the medical system and give suggestions and solutions based on what they have learned from their experiences and from their interactions with other people with chronic illness. Participants also demonstrated a high level of insight and awareness of their feelings but also of other people's feelings, which made them more considerate, compassionate and forgiving. It is clear that all of these dimensions of understanding are necessary to support others that experience similar situations.

4.5.2 Resilience

Kralik et al. (2006) describe resilience as “the ability to create a new sense of personal order from the chaos and disruption brought about by changes” (p.193). It refers the process of adapting to stressful life events such as illness and how a person adapts or overcomes these adversities. Two participants referred to their strengths directly as “*resilience*”, while others demonstrated characteristics of resilience such as understanding the importance of a strong support network to overcome adversities, remaining optimistic and persistent during difficult times.

Being able to appreciate life and not take things for granted such as enjoying life as much as possible, especially when having a “*good chronic pain day*”, was mentioned by five participants. Among them, Eva and Stella's interviews were particularly revealing:

But now I appreciate a lot of things, even the little things like if I wake up and I'm having a good day pain, I really appreciate it, you know. For like at least three years, I lived every day in constant pain, shoulders burning, pain all over and there's not one day that I wake up and not remember that because when you're kind of on the other side of it, your body just never forgets it so I appreciate you know, the little health, not the little health but the health that I do have now. – Eva

I was literally dying, and I had to learn to walk again. And that was incredible. Like that was really really cool to literally feel every muscle in my body and every little steep hill I could feel in my muscles every sort of incline I could feel it in muscle, and it was a really really cool experience in that having someone teach me how to walk again was priceless... I could never put a price on that, that was incredible. Yeah, I don't know like a lot of strength that comes from within. – Stella

You know horseback riding, I don't think I took it for granted before but I really appreciate the fact that I can still do it because some people can't you know, do things like that. Yeah, so I think it's just made me more grateful and it's helped me focus on things that add value to my life and that genuinely make me feel good.- Eva

Having the ability to find positive aspects in difficult times demonstrates a lot of resilience and makes people appreciate moments when they are feeling well. One participant also spoke to the

importance of perseverance and “*toughing it out*” through difficult times, which also made her more grateful of good moments.

Two participants talked about the importance of educating people about things they were passionate about, and taking on a role of activism:

I don't shy away from educating people on different spinal cord issues and a lot of them say “Oh my God, you know, how did that happen to you when you are so young?” It was just happenstance, its rare and a lot of people feel pity, like... they say I'm so sorry, I don't want that and I feel that they don't see the positive aspects like I'm still lucky, yeah I'm still driving my kids to different places – especially when it's my right foot that's affected – I got lucky. Priya

[...] you know, I sent some emails to Jim Watson, I said : I was downtown at a City of Ottawa meeting cuz I work for the city and your disabled bathroom is not acceptable and (I sent) pictures, and sent it to Jim... and they better address it and once I get there (at City Hall) I'm going to make sure it's done. – Mala

Both recognize the importance of advocating for themselves and others even when they are not always heard and have challenges of their own. Even when things get difficult, they take on the responsibility of educating others and ensuring change happens for the wellbeing of others. Two participants also mentioned that their conditions has made them “grow up faster” and develop certain strengths such might not have developed otherwise:

[...]it made me kind of mature and grow up faster. Just kind of knowing you know, like what's important I think learning how to speak up for myself. I am a relatively shy person so like try to learn how to say the things like what I need and what I want. – Jada

[...] I am disabled, I don't think it's really changed me...it's just made me know that I'm a pretty strong adult – Mala

Finally, five participants mentioned the importance of connecting with others and building a support network to gain a better perspective on other people's experiences as well as on their own experiences. Kralik et al. (2006) mention that resilience is said to be facilitated by connecting with others, and all participants mentioned the importance of connecting with people to overcome the difficulties of chronic illness, either by connecting through support groups or by maintaining relationships with people who can be understanding of their situation.

4.6 Discussion

The following section will provide an interpretation of the results presented in the analysis and will argue that the experience of young adults with chronic illness is highly dependent on social

context and on current dominant ideologies of ableism and healthism. The first section will explore both ideologies and how they influence expectations relating to young adulthood. The second section will identify discrimination experienced as a result of social expectations. The following section will consider how both ability expectations and healthist culture result in internalized oppression. Finally, I will suggest that the positive aspects as described by respondents are developed in opposition to the current dominant ideologies.

4.6.1. Ideologies of ableism and healthism and expectations relating to young adulthood

Whether as a result of everyday interactions with people in their immediate social circle or environment, respondents reported feeling pressure to conform to various social expectations. The expectations identified by young adults highlight how young adulthood is currently understood in contemporary Western Society, through the ideologies of ableism and healthism.

Current western expectations relating to adulthood are characterized by ability expectations and normative standards relating to responsibility, independence, work and activity abilities among others (Burch, 2017). These neoliberal ideologies represent what it means to ‘successfully transition to adulthood’. Essentially, one’s ability to achieve what is expected determines if they are successfully transitioning into adulthood or not. Interestingly, these expectations give the false impression that there exists ‘normal’ or attainable ideals/standards of both ability and health that all need to live up to (Puar, 2017). According to Puar (2017), the goal of these ideologies serves to justify and maintain the exclusion of people with disabilities, notably as considering them as “other”. Results from this study have demonstrated that young adults with chronic illness often feel pressure to attain these ideals, also identified as pressures to be ‘healthy’, to ‘get better’, to be productive members of society, to aspire to have a ‘normal life’ involving work, getting back to work and enjoying life. The difficulty to live up to some of these expectations could then result in exclusion and internalized ableism, as will be described later.

Expectations related to the ideology of healthism also emerged as a theme throughout this study as they shape expectations related to adulthood. According to Gibson et al. (2015) the current neo-liberal, Western context privileges an ideology of ‘healthism’ that values a discourse of ‘individual responsibility and empowerment’ and encourages the ideals of individualism, consumerism and self-determination in relation to health. It is also within this ‘healthist’ discourse that social expectations relating to young adulthood are constructed (e.g. such as expectations to

be healthy when young and shoulder responsibility for the status of their conditions) (Steinberg et al., 2015). Although very few studies examine the link between the construction of young adulthood and expectations relating to health, results of this study demonstrate that there is a need to consider how the current ‘healthist’ context promotes individual-oriented approaches to cope with social expectations, including expectations of young adulthood. For example, one participant attributed the difficulty to fulfill her social roles as a young adult (such as completing graduate school, living independently and being in a stable relationship) as a personal failure due to her poor medical management skills. Additionally, several participants considered one’s ability to self-manage as a personal characteristic dependent on one’s ability to work towards ‘health’ to achieve (or become closer to achieving) a normative ideal of health. They felt that mastering this skill would then allow a person to fulfill what is socially expected of them. If self-management is understood as a set of skills and behaviors that allow people to live up to social expectations, one could understand that a failure to self-manage, would result in personal responsibility and blame for not having developed the necessary skills to do so. It could also serve to maintain “normative expectations of ableism” (Kattari et al, 2018) The ideology of responsibility seems to shape expectations of adulthood: the normalizing discourse of ‘healthism’ which encourages regulating behaviors through responsibility determines if young adults are fulfilling their responsibilities as young adults or not. Effective management of their conditions implies that they are successful at regulating their behaviors and consequently determines if they can successfully attain social expectations whereas poor management skills could result in personal responsibility for their difficulty in fulfilling expectations.

Considering how these pressures reflect both ableist and healthist ideologies seems important because it helps us identify the beliefs and values that define these ideologies (a culture that values health, absence of disease, responsibility, independence and self-management as a strategy to manage chronic illness) and help challenge existing understandings that consider chronic illness as a personal responsibility. The results of this study highlight some of these expectations and point to additional expectations experienced by young adults with chronic illness. On the one hand, they are expected to meet expectations typically expected of young adults, while in the other, they feel besieged with the challenges of having a chronic illness at a young age, such as dealing with discriminatory behavior and getting recognition or being socially excluded as well as dealing with the guilt and fear of being unable to attain what was expected of them. The way

illness is experienced is then dependent on expectations that are directly tied to sociocultural factors. We could ask ourselves if or how illness could be experienced differently if we were living in different social contexts where ableist and healthist expectations weren't the dominant ideologies of current contemporary Western society.

4.6.2. Discrimination experienced as a result of ableist expectations

Discrimination as a result of interactions with strangers and with people in their social circles was a theme that came up in almost every interview. This is consistent with research by Kattari et al., (2018) that shows how discrimination related to ableism is often the result of others' actions, such as ableist comments and behaviors. Participants in this research experienced being called out by others such as family members, coworkers, friends and strangers for using priority seating at the front of the bus or were subject to other people's comments expressing disbelief, assumptions about laziness or feeling that they were exaggerating their conditions. These discriminatory practices reflect ableist expectations related to age (e.g. being too young to require a seat at the front of the bus or being expected to recover from their illnesses).

Discrimination in health-care settings as a result of ableist behavior was also an overarching theme present in almost every interview. Most respondents stated that a medical diagnosis helped them justify their impairments and gain recognition from both the medical community and from people in their social environment because they felt as though their condition(s) were then legitimized. By subscribing to the medical model of disability, they felt that a medical diagnosis would help them receive social recognition as it reflects what is typically expected. However, many respondents stated that after receiving a medical diagnosis, they were confronted with yet more ableist expectations that prevented their illnesses from being recognized by the medical community and others. Participants thus experienced discrimination as a result of stigmatizing comments by doctors and healthcare professionals with expectations and comments such as: *"you're young, you'll heal, you'll be fine"*, or were refused medical care or diagnosis for their conditions because they were expected to get better due to their age; others were not taken seriously because they 'looked fine', etc. This lack of recognition from the medical community highlights the prominence of the model of disability but also the importance of considering other ableist social expectations in perpetuating discriminatory practices.

4.6.3. Internalized oppression as a result of dominant ideologies

According to Campbell (2010), for internalized ableism to exist, there needs to be a presumption of “compulsory ableness”, which considers disability as something less than ideal and abnormal. By considering disability or chronic illness as a problem, we are accepting the concept of ableism just like we do with racism by implying that some races are superior than others. Societies’ general acceptance of ableism often results in the internalization of ableist ideologies such as self-loathing, self-blame or perceiving impairments as undesirable. Although ableism is not always easily identifiable, the results of this study suggest that young adults internalize certain ability expectations. On the one hand, respondents expressed frustration, shame and guilt for their conditions and their ‘inability’ to live up to social pressures and, on the other, took it upon themselves to become ‘successful’ self-managers of their conditions and educate others about their specific impairments or conditions.

Several participants recounted positive experiences of getting social recognition from people in their social environment (such health care professionals, coworkers, friends and family, etc). Yet, participants also stated that even though they occasionally felt understood, they also felt guilt (e.g. for requiring accommodations, for having to call in sick at work) and fear (e.g. fear of being perceived as ‘lazy’ if they requested accommodations, fear of not being able to keep up with work expectations because of illness, etc.). This suggests that even when others are generally understanding and accommodating, the need to conform to ableist social expectations can be internalized and taken on as personal responsibility. For example, some respondents expressed denial of their conditions by stating that they were continuously looking for a cure or a better treatment or having goals of ‘getting back’ to the activity level they had before, from fear of having to live with their conditions for the rest of their lives. Although denial was explained as a strategy to remain hopeful that they would not have to deal with debilitating impairments for the rest of their lives, participants also stated doing so to avoid accepting that they might not be able to fulfill the expectations of adulthood (such as dating, having a stable career or a family, etc). These examples then highlight how ability expectations are internalized as participants contribute to the belief that one must aspire towards normalization and in treating impairment as an ‘undesirable state’.

Participants also considered the development of self-management skills as essential to become successful self-managers and perceived self-management positively largely for two

reasons: to feel empowered and in control of their health and to minimize the symptoms of impairment. Young adults own perceptions of their role in the management of their conditions can be interpreted as internalized ableism on two accounts : on the one hand because it reaffirms dominant ideologies that consider illness as individual ailment and a personal responsibility that can be managed, and on the other, it implies that one must aspire towards the 'norm', in this case, attaining an ideal of health.

For some participants, self-management was understood as a set of skills and behaviors that were dependent on personal characteristics and one's ability to work towards achieving 'health'. In this perspective, when a person struggles to manage their condition it is considered a personal issue that can be resolved with better management. The effective management of one's condition was considered important to minimize impairments (such as pain, fatigue, depression) but also to allow them fulfill some of their roles and *"take part in life", "be productive at life", "do what's required in order to be active in society", "succeed at my job"*. Goal setting, pacing strategies, medication management, energy conservation and pain management with exercise were all common strategies identified to manage the effects of the impairments and to allow them to take part in life and fulfill some of their roles (e.g. as a mother: *"conserve energy for my kids"*, as a student: *"read on meditation and how to deal with pain without any drugs to go back to school"*, etc.). Therefore, a person's ability to maintain an active life and fulfill social expectations and roles (such as work, live independently or fulfilling roles as a parent) was associated with a higher level of self-efficacy or a mastery of self-management skills. For the most part, young adults perceived these strategies as *'empowering'*, and as a way to *"take ownership"* of their health but also allowed them to *'live normally'* and enjoy life.

This perspective demonstrates how the 'healthist' discourse is not just part of dominant ideologies but can also be internalized by those who believe their health and conditions are dependent on personal characteristics or their ability to control and become successful 'self-managers' (Crawford, 1980). Gibson et al (2015) consider the empowering effects of 'healthist' ideology, while reminding us of the importance of considering how individuals are "cast as accountable and are socially required to demonstrate their ability to maintain health or otherwise account for their ill-health"(Gibson et al, 2015 : 133). This perspective allows us to consider how 'empowerment' could be considered problematic because it implies that young adults are primarily

responsible for the management and the outcome of their conditions. It is easy to imagine how a persons' choice not to engage in self-management practices, or a person's difficulty in adhering to certain practices, could result in stigma as their disengagement could be perceived as a lack of effort or even as a contribution to the deterioration of their condition. It is interesting to note that young adults feel the pressure from their environment to manage their conditions (such as when receiving suggestions on how to better manage their conditions) yet have similar expectations towards other young adults living with chronic conditions. Finally, participants shared thoughts and beliefs that indicated that self-management skills made them feel less responsible for the status of their conditions as several participants stated that without self-management strategies, they feared being "*sad, depressed and not doing anything*", or risked "*staying at home or on the couch all day*" which motivated some to "*not to be that person*". Similar statements also represent internalized ableism as they imply that people with chronic conditions are indeed 'lazy' or are perceived negatively if they are not doing everything possible to aspire towards the 'norm'.

Educating others about their illness and impairments was described as a common occurrence in order to justify impairments and as hope to get social recognition from others. Interestingly, young adults stated that explaining and communicating to others did necessarily result in greater recognition. For example, when engaging with people such as doctors and healthcare professionals who are generally expected to have an expertise and a high level of understanding with regards to chronic illness, respondents stated it was often during these interactions that they felt the most dismissed and misunderstood. In turn, respondents described looking to people that were more understanding for support but also excused and justified others' behaviors for their lack of understanding. Comments such as : "*you can't blame them*", "*it's not their fault*", "*it's understandable*", "*chronic pain is different for everyone so it's really hard for people to understand*", "*it's emotional immaturity*" , "*they don't mean to blame*" excuse behaviors that actually perpetuate discrimination. Excusing others' behaviors not only demonstrates that young adults have, to some extent, accepted the idea that their illness makes them 'other' or different but also reinforces and contributes to the erroneous belief that chronic illness is difficult to understand. It may be helpful to consider this 'lack of understanding' as stigmatizing behavior that is the result of a culture that encourages ableist and ageist ideologies. This 'lack of understanding' also highlights ableist expectations that consider illness as an individual issue because the person that experiences the illness is held responsible for their condition and for

educating others about their ‘other’ status or identity “other than one’s own” (Campbell, 2010 : 26).

Participants also stated taking on the role of educators to justify when they could not participate in ‘normal’ day to-day activities. For example, a participant stated working part-time because of fatigue and pain but having to continuously justify to her colleagues and others why she could not return to full-time work. In this sense, young adults are often conscious of the limits of self-management yet have to explain to others when they are unable to fulfill what is socially expected, even when self-management skills allow them to take part in social activities at their own pace. Explanations and justifications seem to be important aspects of self-management because it helps young adults justify their current situation and perhaps demonstrate to others that they are indeed ‘working’ towards improving their condition by trying various strategies and accepting suggestions.

4.6.4. Positive aspects of living with a chronic illness and dominant ideologies

Participants were asked to identify some of the positive outcomes of having a chronic condition at a young age because these are rarely recognized or valued in society. However, being attentive to the positive value of lives lived with chronic illness not only helps us recognize some of the strengths that most often remain unnoticed, but it allows us to interpret what those strengths reveal about current conceptions of disability and adulthood. In certain instances, participants described having developed specific skills as a result of their impairments. In other words, these strengths were developed because of the effects of their impairments (such as developing resilience, perseverance and ‘toughing it out’ as a result of continuous and debilitating chronic pain). However, it seems relevant to consider if some of the positive aspects and skills are developed in opposition to the current context in which they are experienced. More precisely, could skills and strengths such as resilience and understanding be developed in opposition to the current ideologies of ableism and healthism?

As previously discussed, ableist ideologies result in discriminatory behavior that perpetuate inequalities. Young adults in this study identified the lack of understanding from people in their social environment as a major issue as they often felt dismissed for their conditions, as though they were not taken seriously, and instead judged and perceived negatively. It is interesting to note that participants stated having developed a high level of understanding of the same factors to which

they attributed society's lack of understanding. That is, understanding the implications of having a chronic illness at a young age, the invisible aspects of impairment and the importance of empathy during social interactions. It seems relevant to question whether the sensitivity and awareness developed by young adults is in fact a positive outcome of ableist ideologies that generally fail to acknowledge and recognize young adults' conditions and realities.

Several participants also stated that due to their conditions, they had evolved into more mature, responsible, strong and independent adults quickly. Some were also actively involved in social activities and groups and were actively involved in the management of their conditions in order to participate in society. In opposition to the ableist ideologies that consider people with disabilities as less capable individuals who are less likely to contribute and participate actively in society (Parent, 2017), young adults stated that not only were they actively engaged in society, they also had developed certain qualities that other young adults might not have developed at all. We could also ask ourselves if these qualities were developed in opposition to ableist discriminatory practices; that is, do young adults develop certain qualities not only to reject common conceptions of disability but also to prove that they are in fact capable individuals?

CHAPTER 5: IMPLICATIONS FOR SOCIAL WORK PRACTICE

The objective of this chapter is to propose implications for social work practice and suggest appropriate intervention methods. The first section will describe young adults' suggestions and the following section will discuss implications for social work practice and make suggestions for social work practice as well as academia.

5.1 Participants suggestions

When respondents were asked what type of programs or groups would be useful for young adults with chronic illness, seven out of eight respondents mentioned that having support groups specifically for young adults would be beneficial. There were two principal reasons for this suggestion. First, it would allow them to connect with people of their age and to better relate to some of the implications of having a chronic illness at a young age. Many considered having a chronic illness at a young age as a completely different experience than having it later in life and consequently stated having difficulty relating to older people. Whether it be because of discrimination and stigma experienced at a young age or because of the pressures and social expectations specific to their life stage, it was stated that support groups for younger people would allow them to meet people who understand the implications of having a chronic condition at a young age. Victoria explains : *"I see on the Facebook page, there's like maybe two people that are young that comment a lot and I really kind of echo what they're saying, I completely like wholeheartedly, I'm like...that's exactly how I feel."* Several also suggested support groups to break isolation because they stated feeling lonely, isolated and as though they didn't have anyone to talk to or to share some of their experiences with. In this sense, support groups would allow young adults to meet people and feel as though they are not alone. As stated by one respondent, having a *"community of people who get it"* is extremely important to make connections and it could allow for conversations about different topics not typically discussed, such as how others 'show' their invisible disabilities to others (e.g. a card to display in public) to get social recognition. Therefore, having a group for young adults would provide a space for discussion about topics that are rarely discussed and encourage a sense of community to break social isolation.

Another suggestion brought forward by two participants was the importance of having a person accompany them to *"coordinate things and help navigate the system"* as well as advocate for them when experiencing discrimination. For example, when going to medical appointments and feeling as though they were not being taken seriously or believed, a social worker could help advocate for them and denounce discriminatory practices or behaviours. Several participants also

mentioned feeling alone and overburdened by some of the tasks they had to take on by themselves (such as navigating the health-care system, making appointments and doing research about different treatment options or support in the community) and suggested having a social worker to help with coordination and management.

Several participants considered empathy as essential but missing in most social interactions and from support services. A person's ability or willingness to understand how difficult it can be to get by on a day-to-day basis was considered one of the most important required skills within social interactions. This would allow them to get approval, validation and as though they are not to blame for what they are experiencing. It was considered important mostly because it impacts the quality of their interactions, relationships as well. Interestingly, being able to understand the implications of having a chronic illness at a young age, being able to relate and empathize with others and to understand the fluctuating nature of chronic illness were described as strengths gained by young adults with chronic illness over time as a result of their experiences.

5.1 Implications for social work practice

The previous chapters have demonstrated how oppression and discrimination operate at different levels (personal, institutional, structural) and how this can often result in internalized oppression. I would like to propose engaging in anti-oppressive social work practice to address some of the discriminatory practices and behaviours that have been identified by young adults. In the following section, I consider how participants' suggestions might be integrated to anti-oppressive social work practice through individual, group and structural interventions.

5.1.1 Anti-oppressive practice in social work

There are several different theories and approaches that inform anti-oppressive theory and practice (Mullaly, 2010), notably critical social work theory like critical disability theory, the theoretical paradigm guiding this research. Essentially, anti-oppressive practice (AOP) is an approach in social work that challenges structural inequalities of certain social groups as a result of dominant social structures, such as the health-care system as discussed above (Mullaly, 2010). As previously stated, young adults with chronic illness often constitute a group of individuals that experience discrimination, also identified as ableism. This approach in social work addresses discriminatory practices in ways that challenge systemic discrimination rather than using other intervention paradigms such as behavioural or psycho-social approaches that primarily focus on individual

behaviour or personality. AOP in social work can take many forms but essentially follows a set of common principles that guide most practices, whether it be through individual, group or structural interventions. Some of these key guiding principles include considering the needs of vulnerable persons and increasing their involvement in many aspects of society as well as critiquing existing social structures in order to change them and reduce social inequalities (Mullaly, 2010).

Most respondents identified support groups as missing despite the fact they are a very much needed type of support for young adults with chronic illness. There are typically two types of groups within traditional social work practice: task groups and treatment groups (which include therapy, support, education, personal growth and socialization groups) (Roy and Lindsay, 2015). Support groups are typically considered as ‘treatment groups’ and are particularly useful.

Participants’ main suggestions were support groups, also considered as ‘treatment groups’ which are frequently used to break isolation and allow participants to identify commonalities as opposed to ‘task’ oriented groups that typically focus on ‘problem-solving’ with specific goals or objectives. A similar group would be beneficial to break the isolation and enable young adults to become more active and connect with other young adults in similar situations. As previously discussed, a common effect of oppression and discrimination is social exclusion, which often results in isolation. These types of groups would also help foster an environment for empathetic and emotional support, notably as most of the participants have lived similar experiences and can relate to one another. These types of groups would also be beneficial in that they could help take a step away from a lens of personal responsibility, as young adults would become aware of the similarities in the discriminatory practices they have experienced. A social worker adopting an anti-oppressive approach could guide the group by bringing awareness to the existence of certain discriminatory practices and structures of oppression (e.g. ableism) and by framing them in larger socio-cultural contexts. The aim would then be to ultimately challenge current social practices and structures to bring about change.

Although not mentioned by participants, popular education is another type of ‘treatment group’ typically privileged in community development that is characterized by learning methods that value “education for critical consciousness” (Walters & Manicom, 1996). A key element of this type of group is its commitment to promoting social justice because it aims to create a sense

of awareness about the world we live in and the context in which many problems arise (ibid). This would give young adults the opportunity to reflect on their own experiences, identify commonalities but also become more aware of discriminatory practices they might experience and situate the problem outside of themselves. This type of group could also challenge common understandings of chronic illness and disability and conceptualize them as cultural constructs rather than personal problems.

The principal goal of anti-oppressive practice is to make changes on a more structural level (Pullen-Sansfaçon, 2013). This means challenging oppression through collective action, advocacy, policy change and activism (Mullaly, 2010). Some participants already mentioned being involved in similar actions. For example, Mala talked about her experience advocating for accessible bathrooms at the City of Ottawa by writing an email and sending pictures to the mayor. Others mentioned needing support to advocate for themselves because living with a chronic illness can be tiring and because impairments can make it difficult to take action and advocate. Social workers could have an important role by accompanying those who would like to challenge discriminatory behaviours and/or oppressive practices. For example, since many participants talked about experiences of discrimination within the health-care system, a social worker could accompany them during appointments and ensure that their rights are respected while at the same time offering support during such challenging experiences. Social workers could also offer support for advocacy activities such as help writing letters to MPPs or to Prime ministers to express concerns about certain matters, participate in events and committees, etc. There are various ways that social workers could offer support and encourage actions to promote changes on a more structural level.

It also seems that a significant amount of work needs to focus on challenging what has been discussed throughout this paper: challenging existing ableist norms and expectations. This is not an easy task as ableism is so ingrained in culture and society that often times, it seems like ableist actions and behaviours are impossible to recognize. We really need to challenge dominant ideologies (such as able-bodied ideologies) that consider that managing behaviours or attitudes, such as self-management, are useful methods of ‘treatment’. Of course, a possible implication for social work practice would be to ensure social workers are educated about the realities of ableist behaviour, to prevent them from being reproduced and to develop appropriate services and groups. However, this seems insufficient. There needs to be a much greater awareness about the reality of

living with a disability and/or chronic illness, especially at a young age. Social work could play an important role in challenging the common conceptions of ability and in educating others about the various structures of oppression (e.g. neoliberalism, ableism, etc.). Social workers within social justice organizations have the ability to develop services, programs and approaches that can challenge discrimination and oppression. In the Ottawa/Outaouais region, there are few support and advocacy groups solely for disability related matters (e.g. Citizen Advocacy, Reach Canada). However, other advocacy organizations such as Droits-Accès de l'Outaouais, an organization that provides individual and collective support and advocacy for individuals with mental health conditions, could serve as a model for disability and/or chronic illness related matters.

Finally, I would like to encourage students, professors and researchers to share and disclose some of their personal experiences with chronic illness and disability as it often seems to be overlooked. This could be an interesting way to challenge common conceptions of disability, to raise awareness about the various ways disability is constructed and reproduced normatively, and to allow people with disabilities to share some of their experiences. However, for this to happen, there needs to be inclusion of young adults with disabilities and chronic conditions in academic settings, as they are still largely absent and excluded from most University settings (Titchkosky, 2011). This form of structural inequality requires us to rethink the many ways that universities and academic settings remain inaccessible to all and exclude many groups such as young adults with disabilities and chronic conditions. By normalizing the absence of disability, such institutions continue to exclude people that have valuable experiences that could be shared in order to bring meaningful changes in academia. They also prevent many young adults to access the higher education they are entitled to. Students with disabilities need to be included not only in social work programs but in other university programs as well. Lastly, social work researchers could include people with disabilities in research, for example through participatory action-research (Strier, 2006). This could help build knowledge by considering the expertise and lived experiences of young people with chronic conditions, address some of their realities and propose concrete intervention strategies.

CONCLUSION

The purpose of this study was to highlight the diversity of lived experiences of young adults living with chronic illnesses and to interpret the meaning attributed to these experiences. The results of this study show that the experience of young adults with chronic illness is highly dependent on the current social context that privileges ideologies of ableism and healthism. Central to the experiences described was discrimination as a result of ableist expectations and the pressure to attain these normative expectations, while having to also manage a chronic illness. The pressure to attain these ideals, also identified as pressures to be 'healthy', to 'get better', to be productive members of society, to aspire to have a 'normal life' involving work, getting back to work and enjoying life were the principal challenges resulting from ableist ideologies. For these young adults, illness has presented itself as another hurdle specifically because of the stage of life they are in.

The analysis enabled me to address the four objectives of this study: first, I described how young adults' social environments influenced their relationships and their struggles for social recognition. Second, I described the specific challenges and experiences of discrimination young people with chronic illness experience as a result of the normative expectations of ableism. The third objective of the study identified individual responsibility and self-management practices as strategies developed by young adults to cope with social expectations. Finally, respondents stated that resilience and understanding were the two main positive aspects of living with a chronic illness at a young age.

The analysis and the discussion further developed ideas based on the experiences shared by participants. The key findings demonstrate that young adults with chronic illness experience internalized ableism as a result of the dominant ableist and healthist ideologies. As a result of various social expectations, I suggested that young adults internalize certain ability expectations that affect how they perceive themselves and how they interact with their social environment. The current 'healthist' discourse promotes the idea that the management of chronic conditions is dependent on personal characteristics and one's ability to overcome the difficulties associated with their conditions. Additionally, participants stated taking on the role of educator to justify and explain their conditions to others in their social environment.

This study differs from other research on the experience of chronic illness because of its specific focus on young adults' experiences which has largely been dismissed from academia. By

considering alternative ways of analyzing chronic illness, notably through a social constructionist analysis of disability and the phenomenology of impairment, this study brought forward discriminatory practices as experienced by young adults and analyzed the effects of these practices. This analysis also highlighted the positive outcomes of living with chronic illnesses which are rarely recognized or valued in society. As a result of this analysis I proposed concrete ways to challenge discrimination through anti-oppressive social work practice to address some of young adults' needs as well as make changes on a more structural level through collective action, advocacy, policy change and activism.

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ANNEXES



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Annex 1: Interview guide for participants

NOTE: The following questions will serve as a guide for the interview but will be adjusted based on the responses received from the participants. The following interview is divided in 4 themes: A. [Chronic illness & Social Context], B. [Young Adults with Chronic illness], C. [Self Management Practices], D. [Opinion Questions]

INTRODUCTION

- Introduction of the interviewer and participant
- Signature of the consent form and answering any question the participant may have before the interview starts.
- Ask the participant: What words would you be comfortable using when referring to your condition (s)?

A. CHRONIC ILLNESS & SOCIAL CONTEXT

1. Do you know the causes of your illness or condition? If so, what do you think are the causes?
2. What areas of your life are affected by your chronic condition?
3. Are you currently employed and if so, what kind of supports are available at work?
4. How does your social environment (family, friends, students, co-workers, acquaintances, etc.) react when you are not doing well?
5. How does your social environment react when you are in seemingly 'good health' or when you are having a 'good day'?
6. What kind of overall support do you get from the people in your social environment? (could be at work, or in your close relationships)

B. YOUNG ADULTS WITH CHRONIC ILLNESS

7. In your opinion, do you find that you experience specific challenges or barriers as a young person living with a chronic condition?
8. Is there anything you wish people understood better about being a young adult with a chronic condition?
9. Has there been any positive outcomes of living with a chronic condition at your age? (any positive aspects)
10. Do you perceive yourself as an adult? Why or why not? Can you explain? (Follow-up question, if not already answered: Do you think your chronic condition has affected how you perceive yourself as an adult?).

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C. SELF MANAGEMENT PRACTICES

11. What are some of the practices you use to self-manage your condition? Where and how did you learn these practices? (Definition if necessary: self-management refers to the tasks a person takes to take control of their condition or illness through their actions and behaviours such as eating right, exercising, getting a good night's sleep, etc.)

12. Have you ever participated in a self-management workshop for managing your chronic condition or the symptoms surrounding it? (give examples if needed: exercise, relaxation, anxiety, etc.)

If yes:

13. What has brought you to participate in a self-management workshop for managing your chronic condition or the symptoms surrounding it?

14. How would you describe your experience within self-management groups?

15. Did you find you could relate to the content provided in session?

16. Do you think that the current self-management programs accurately take into account the reality and needs of young adults with chronic conditions?

If no:

17. Have you ever considered participating in a self-management program for managing your chronic illness and /or has anyone ever suggested that you participate? If so, is there a reason why you chose not to participate?

Both :

18. Do you consider self-management skills essential to manage your condition?

19. What type other programs or groups would be useful for young adults like yourself, who live with a chronic condition?

D. OPINION QUESTIONS

Do you agree or disagree with the following statements?

- a. When all is said and done, I am the person who is responsible for taking care of my health. Can you explain your answer?
- b. I have trouble getting recognition for my illness (replace with condition if more suitable) and find myself having to explain to others that my symptoms are real, genuine and/or severe. Can you explain your answer?



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Annexe 2 : Grille d'entretien pour les participants

NOTE: Les questions suivantes serviront de guide pour l'entrevue, notons toutefois que ces questions seront ajustées en fonction des réponses obtenues des participants.

INTRODUCTION

- Présentation de l'interviewer et du participant
- La signature du consentement et répondre à toutes les questions que pourrait avoir le participant
- Demander au participant: Quel mots serais-tu à l'aise d'utiliser pour parler de ta condition?

A. CONTEXTE SOCIAL ET LES MALADIES CHRONIQUES

1. Selon toi, quelles sont les causes de ta maladie chronique?
2. Quand est-ce que ta maladie chronique pose-t-elle problème dans ta vie ?
3. Comment ton entourage (famille, amis, collègues, étudiants, connaissances, etc.) agit-il quand tu vas moins bien ?
4. Comment ton entourage (famille, amis, collègues, étudiants, connaissances, etc.) agit-il quand vas bien ou quand tu as une 'bonne journée' ?

B. JEUNES ADULTES AVEC MALADIES CHRONIQUES

5. As-tu l'impression que tu rencontres des défis particuliers puisque tu as une maladie chronique à un jeune âge ?
6. As-tu l'impression que ta maladie chronique affecte ta perception d'être adulte ?
7. Y a-t-il quelque chose que tu aimerais partager avec les autres pour qu'ils puissent mieux comprendre les réalités des jeunes adultes avec des maladies chroniques ?
8. À ton avis, est-ce qu'il existe des aspects positifs de vivre avec une maladie chronique à un jeune âge ?

C. PRATIQUES D'AUTOGESTION

9. Quelles sont les pratiques que tu utilises pour gérer ta maladie chronique ? Comment as-tu appris à employer ces pratiques-là ?

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10. Qu'est-ce qui t'a amené à participer à un programme de gestion pour les maladies chroniques ?

Si oui:

11. Qu'est-ce qui t'a amené à participer à un programme de gestion pour les maladies chroniques?

12. Comment décrirais-tu ton expérience au sein du programme de gestion des maladies chroniques ?

13. Avais-tu l'impression que la matière partagée lors des sessions était pertinente pour toi ?

14. As-tu l'impression que les programmes d'autogestion pour les maladies chroniques tiennent compte de la réalité des jeunes adultes ?

15. Penses-tu que les pratiques d'autogestion sont nécessaires afin de gérer ta maladie chronique ?

Si non:

16. As-tu déjà considéré participer à un programme de gestion pour les maladies chroniques et/ou est-ce qu'on déjà suggérer de participer? Si oui, y-a-t-il une raison pour laquelle tu as décidé de ne pas participer?

Les deux :

17. Penses-tu que les pratiques d'autogestion sont nécessaires afin de gérer ta maladie chronique ?

18. Quels types de programmes souhaiterais-tu voir dans la communauté pour les jeunes adultes avec des maladies chroniques ?

D. QUESTIONS D'OPINION

Es-tu en accord ou en désaccord avec les énoncés suivants :

a. Je crois qu'en fin de compte, je suis la personne responsable de gérer ma santé.

b. J'ai de la difficulté à faire reconnaître ma condition de santé à mon entourage et je dois expliquer aux autres que mes symptômes sont réels et/ou sévères.

Annex 3 : Characteristics of Participants

Pseudonym	Age	Sex	Condition/illness	Occupation
Sasha	20	Female	ITP (Immune thrombocytopenia) and FM (Fibromyalgia)	Student
Mala	33	Female	Spinal cord injury for two years	Librarian
Stella	26	Female	Chronic migraines	Unemployed, Ontario Disability Support Program (ODSP)
Eva	35	Female	Nerve pain	Support analyst at a hospital
Victoria	33	Female	Cervical disc bulge and annual tear	Federal public service employee, currently on long term disability
Jada	27	Female	Undiagnosed chronic pain. Does not identify with diagnosis received.	Front-desk assistant at a hotel
Priya	35	Female	Spinal cord condition	Health care professional, currently on long term disability

Annex 4 : Consent Form

**Title of study: Self-management and chronic conditions :
exploring young adult's experiences**

Name of researcher : Anne MacKay –email : amack047@uottawa.ca
Faculty of Social Sciences –School of Social Work

Supervisor : Marc Molgat –email : marc.molgat@uottawa.ca
Phone number : 613-562-5800 Extension : 6710
Faculty of Social Sciences –School of Social Work

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Anne MacKay, under the supervision of Marc Molgat. This research is conducted as a part of a master's research paper and is not funded or sponsored. The purpose of this document is to illustrate the objectives of the study and the implications of my participation in this study if I would like to participate or not. If I require additional explanations or clarifications, please do not hesitate to ask questions at any time.

Purpose of the study : The purpose of this study is to gain a better understanding of how young adults perceive their role in the management of their chronic condition(s) and propose appropriate intervention methods for young people.

Participation: The project is being conducted independently from the groups from which I may be recruited. My participation will consist of attending one interview session of approximately one hour and a half during which I will be asked to answer questions asked by the researcher as best as I can. I will have the option to request multiple short interviews instead of one if the duration of the interview is too long. I can also take breaks at any time, walk, stretch or request any accommodation that is required to ensure my well-being during the interview. The interview will take place in a location of my choice that ensures confidentiality and the time of the session will be dependent on my availability.

Participation in this research can include an audio recording of the interview, please indicate below if you accept or not for the interview to be recorded:

- ☐ I accept to have the interview recorded
- ☐ I do not accept to have the interview recorded

If you refuse to have the interview recorded, notes will be taken by the researcher instead.

Risks: My participation in this study will entail that I share personal experiences which may have been difficult and this may cause me to feel emotional or psychological discomfort. I have received assurance from the researcher that every effort will be made to minimize these risks. I may stop participating or

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refuse to answer any question at any given time. In case I wish to talk about emotional or psychological discomforts with someone, I can contact Centretown Community Health Centre located at 420 Cooper St. in Ottawa (613) 233-4443 or info@centretownchc.org as they offer walk-in counselling support free of charge.

Benefits: My participation in this study will allow me to reflect on my self-management practices, my struggles or difficulties, which may lead to positive realizations with regards to myself or my environment. My participation in this research will also contribute to the advancement of knowledge, through the comprehension of the social function of self-management in the field of chronic illness and the development of an analytical framework for social work practice in the field of chronic conditions.

Financial compensation: If I choose to participate in this study, I will receive a 15\$ gift card at the *Rideau Centre*. This compensation will be given to me at the beginning of the interview. I will be entitled to keep the compensation if I choose not to complete the interview.

Confidentiality: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used for data analysis following interview transcription. The information that I share will only be used for the purpose of this research. Only the researcher and her supervisor will have access to the research data.

Anonymity will be protected in the following manner: a pseudonym will replace my name in the publication of the results and only the researcher and her supervisor will have access to the codes linking my name to the pseudonym. If I talk about specific people, their names will not be mentioned in the publication. If I talk about a specific establishment, institution or organization, they will not be named in the research.

Conservation of data: The tape recordings of interviews, transcripts and notes will be kept in a secure manner. They will be stored in the locked office of Marc Molgat and they will be protected by a password on his computer. These will be kept for a period of 5 years following the end of the research project and only Anne MacKay and Marc Molgat will have access to them. Following the period of retention, they will be disposed of securely.

Voluntary Participation: I am under no obligation to participate in this study and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be disposed of securely.

Acceptance: I, _____, agree to participate in the above research study conducted by Anne MacKay of the School of Social Work, Faculty of Social Sciences, University of Ottawa, which research is under the supervision of Marc Molgat.

If I have any questions about the study, I may contact the researcher or her supervisor.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall,
550 Cumberland Street, Room 154, (613) 562-5387 or ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

Participant's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Annexe 5 :
Formulaire de consentement

Titre du projet: L'expérience des jeunes adultes au sein de programmes d'autogestion pour les maladies chroniques

Chercheuse principale : Anne MacKay –Courriel :
amack047@uottawa.ca
Faculté des sciences sociales –École de service social.

Superviseur: Marc Molgat –courriel : marc.molgat@uottawa.ca
Numéro de téléphone : 613-562-5800 Poste : 6710
Faculté des sciences sociales –École de service social.

Invitation à participer : Je suis invité(e) à participer à la recherche nommée ci-haut qui est menée par Anne MacKay dans le cadre d'un mémoire de maîtrise et qui est supervisé par Marc Molgat. Aucun financement n'a été perçu par la chercheuse pour mener à bien ce projet de recherche. Le présent document me renseigne sur les modalités de ce projet de recherche afin que je puisse décider si j'aimerais participer ou non. S'il y a des mots ou des paragraphes que je ne comprends pas, je peux poser des questions à n'importe quel moment.

But de l'étude : Le projet vise à comprendre l'expérience des jeunes adultes au sein de programmes d'autogestion pour les maladies chroniques. Le projet cherche aussi à comprendre la façon dont les jeunes adultes perçoivent leurs rôles dans la gestion de leurs maladies chroniques afin de développer des pratiques d'interventions pour le service social.

Participation: Le projet est mené de manière indépendante des groupes par lesquels je serai recruté. Ma participation consistera essentiellement à participer à une entrevue qui durera entre 60 et 90 minutes pendant laquelle je vais répondre du mieux que je le peux aux questions posées par la chercheuse principale. J'aurai l'occasion de demander plusieurs petites entrevues au lieu d'une seule si la durée de l'entrevue est trop longue. Je peux prendre des pauses à n'importe quel moment durant l'entrevue et/ou je peux demander des accommodements afin d'assurer mon confort lors de l'entrevue. L'entrevue est prévue selon la disponibilité du participant et dans un endroit de son choix qui permet la confidentialité et la sécurité.

La participation à cette recherche peut impliquer un enregistrement audio de l'entrevue.

- ☐ J'accepte que l'entrevue soit enregistrée.
- ☐ Je n'accepte pas que l'entrevue soit enregistrée.

Si je refuse que l'entrevue soit enregistrée, des notes seront plutôt prises par la chercheuse.

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Risques : Je comprends que puisque ma participation à cette recherche implique que j'invoque des expériences pouvant avoir été difficiles, il est possible qu'elle crée des inconforts émotionnels ou psychologiques. J'ai reçu l'assurance de la chercheuse que tout se fait en vue de minimiser ces risques. Je peux refuser de répondre à n'importe quelle question ou me retirer de la recherche à n'importe quel moment. Au cas où je voudrais discuter avec quelqu'un en raison de malaises suscités par la participation à l'entrevue, je peux communiquer avec le Centre de santé communautaire du Centre-ville situé au 420 rue Cooper au 613-233-4443 ou info@centretownchc.org puisqu'ils offrent des services de counselling gratuit en français.

Bienfaits: Ma participation à cette recherche me permettra de réfléchir à mon implication dans la gestion de ma condition de santé de façon approfondie, ce qui peut m'amener à des prises de conscience positives sur moi-même ou sur mon environnement. Ma participation à cette recherche aura également des bienfaits dans l'avancement des connaissances, en permettant de comprendre la fonction sociale des pratiques d'autogestion, et de permettre le développement d'un cadre d'analyse pour les pratiques d'intervention en service social.

Compensations financières : Si j'accepte de participer à ce projet de recherche, je recevrai une compensation sous forme d'une carte cadeau du *Centre Rideau* de 15\$. La compensation me sera versée au début de l'entrevue. Si je ne termine pas l'entrevue, je garderai tout de même la dite compensation.

Confidentialité : J'ai l'assurance du chercheur que l'information que je partagerai avec elle restera strictement confidentielle. Je m'attends à ce que le contenu ne soit utilisé que pour l'analyse des données suite à une retranscription de l'entrevue et selon le respect de la confidentialité, les transcriptions d'entrevues vont être entreposées dans l'ordinateur de la chercheuse principale protégé par un mot de passe.

L'anonymat est garanti de la façon suivante : Des pseudonymes seront utilisés pour citer les participants afin de protéger leur identité. Les informations permettant d'identifier le participant seront supprimées lors de la transcription des enregistrements. Ces documents seront seulement accessibles à la chercheuse principale et son superviseur de mémoire. Si je parle d'un organisme ou d'une institution précise, ceux-ci ne seront pas nommés.

Conservation des données: Les données recueillies par enregistrement auditif seront conservées de façon sécuritaire. Les transcriptions seront protégées par un mot de passe dans l'ordinateur du bureau du superviseur du mémoire à l'Université d'Ottawa. Le formulaire de consentement sera conservé dans le bureau fermé sous clé du superviseur de mémoire à l'Université d'Ottawa. Lorsque la recherche sera terminée, les données seront entreposées dans un classeur barré dans le bureau du directeur de mémoire, qui est constamment fermé à clé. Les données seront conservées pour une période de 5 ans après la fin de la collecte de données et seulement le superviseur du mémoire pourra y avoir accès. Après cette période, les enregistrements seront supprimés de façon sécuritaire, et les formulaires de consentement seront déchiquetés.

Participation volontaire: Ma participation à la recherche est volontaire et je suis libre de me retirer en tout temps, et/ou refuser de répondre à certaines questions, sans subir de conséquences négatives. Si je choisis de me retirer de l'étude, les données recueillies jusqu'à ce moment ne seront pas utilisées et seront détruites.

Acceptation: Je, _____, accepte de participer à cette recherche menée par Anne MacKay de l'École de service social de la faculté des études

supérieures et postdoctorales à l'Université d'Ottawa. Cette recherche est supervisée par Marc Molgat.

Pour tout renseignement additionnel concernant cette étude, je peux communiquer avec la chercheuse ou son superviseur.

Pour tout renseignement sur les aspects éthiques de cette recherche, je peux m'adresser au Responsable de l'éthique en recherche, Université d'Ottawa, Pavillon Tabaret, 550, rue Cumberland, pièce 154, (613) 562-5387 ou ethics@uottawa.ca

Il y a deux copies du formulaire de consentement, dont une copie que je peux garder.

Signature du participant: _____ Date: _____

Signature du chercheur: _____ Date: _____

Annex 6 : Certificat d'approbation éthique | Certificate of Ethics Approval

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

11/03/2019

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number
Titre du projet / Project Title

S-02-19-2755
Self-management programs for
chronic illness: exploring young
adult's experiences

Type de projet / Project Type

Mémoire de maîtrise / Master's
major research paper

Statut du projet / Project Status

Approuvé / Approved

Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)

11/03/2019

Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)

10/03/2020

Équipe de recherche / Research Team

Chercheur / Researcher **Affiliation**

Anne MACKAY

École de service social / School of Social Work

Marc MOLGAT

École de service social / School of Social Work

Rôle

Chercheur Principal / Principal Investigator

Superviseur / Supervisor

Conditions spéciales ou commentaires / Special conditions or comments

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