

A Grounded Theory of Empowerment in Cancer Survivorship and Rehabilitation

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## Abstract

**Purpose:** A diagnosis of cancer can be disabling in many ways. Most notably, cancer treatments are toxic and harmful to the body and threaten a person's ability to care for themselves. In addition, cancer and its treatments can affect many dimensions of quality of life, including peoples' abilities to engage in meaningful occupations. However, there are many gaps in the literature surrounding rehabilitation and the ways in which the psychosocial effects of cancer may be addressed by individuals. Empowerment is a concept used to articulate processes of rehabilitation that involves addressing both functional concerns as well as quality of life issues. Yet, empowerment remains a phenomenon not well understood. It is most often defined as a process and outcome of regaining a sense of control and autonomy that is lost due to an illness, but much of the empowerment literature in the context of cancer is written from the perspective of the health care provider. This perspective fails to recognize the processes through which survivors address functional and quality of life concerns leaving a gap in theory and evidence based practice in cancer rehabilitation. The purpose of this dissertation was to develop a grounded theory of empowerment to illuminate its associated processes from the perspective of cancer survivors to answer the following questions: 1) In what ways do cancer survivors define, describe and/or experience the processes of empowerment?; 2) How do cancer survivors describe the emergence of empowerment within various contexts and relationships related to their illness; 3) What are the connections and relationships between processes of empowerment and the commonly held assumptions about this phenomenon?

**Methods:** Data collection consisted of 22 semi-structured interviews with cancer survivors (cancer of the head or neck and/or breast). Interviews explored participants' illness experiences and views of empowerment. I used the social constructivist grounded theory method to analyze and map the processes of empowerment.

**Summary of Results:** Empowerment reflects multiple complex processes. Broadly, empowerment occurred in two dynamic and paradoxical ways. First, empowerment was associated with establishing control over the treatment, management and impact of the illness on participants' daily lives as a means to circumvent a sense of self that was eroding and changing. Secondly, empowerment was described as processes associated with relinquishing control over aspects of the illness deemed irrepressible and incorporating those aspects into a new identity.

**Conclusion:** These two processes illustrate the paradox embedded within experiences of empowerment. The first process is comparable to current evidence-based practice in cancer rehabilitation that has a dominant focus on symptom control to reduce the impact of the illness on daily life. Gaps are more significant in relation to the empowerment processes associated with relinquishing control. These processes enabled survivors to acknowledge and accept the impact of illness as another way to address functional and quality of life concerns. Thus, my findings suggest that there is a need to design a variety of interventions that help cancer survivors live with and adapt to the effects of illness into daily living.

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## **Chapter 1**

### **The Research Problem**

#### **1.0 The Research Problem**

##### ***1.1 Introduction***

There is an ongoing movement in the diagnosis, treatment and post-treatment of cancer to “empower” cancer survivors (Cancer Care Ontario: Ontario Cancer Plan 2011-2015, p. 22; 40; 44). Empowerment has been defined as a process and outcome through which survivors gain control over the decisions and actions affecting their health (Maunsell, Lauzier, Brunet, Pelletier, Osborne & Campbell, 2014; Jerofke, 2013; Bulsara, Ward, & Joske, 2004). Additionally, empowerment has become a topical issue for healthcare practitioners and policy makers because of the increasing number of people surviving cancer itself, but who then live with the consequences of treatments (Thomas-MacLean et al., 2009; McCorkle et al., 2006). Cancer treatments are not only invasive, but they also leave in their wake an array of challenges. For instance, surgery, chemotherapy and radiation treatments can leave survivors with a range of long-term chronic health issues that range from changes to physical appearance (Vickery, Latchford, Hewison, Bellew, & Feber, 2003), chronic pain (Glare et al., 2014), fear of recurrence (Crist & Grunfeld, 2013), and concerns related to mobility (Hidding, Beurskens, van der Wees, van Laarhoven & Nijhuis-van der Sanden, 2014), but also cognitive and sexual functioning (Boykoff, Moieni, & Subramanian, 2009; Gorman, Su, Roberts, Dominick & Malcarne, 2015) as well as difficulties engaging in such fundamental behaviours as eating (Cousins, MacAulay, Lang, MacGillivray, & Wells, 2013), speaking (Kraaijenga et al., 2016) and breathing (Dunger et al., 2015). It is not surprising, therefore, that quality of life for those who are treated for cancer, albeit successfully, would be significantly altered (Turnbull Macdonald et al., 2012; Thorsen et

al., 2011; Howell et al., 2009). Despite these recognized health issues, there are substantial gaps in terms of infrastructure, adequate accessible resources, and evidence-informed practice in cancer rehabilitation for supporting patients in managing and living with the side-effects from cancer treatments (Silver et al., 2015; Crevenna, 2015; Egan et al., 2013; Mcewen, Egan, Chasen & Fitch, 2013). Cancer rehabilitation is an area of care specific to improving functioning and reducing disability from a diagnosis of cancer and its treatments (Egan et al., 2013; Gilchrist et al., 2009). To develop ways to address gaps specific to this area, survivors are being asked to take a more informed and active role in managing their own health (Howell et al., 2016; Foster et al., 2015; McCorkle et al., 2011). This increased level of responsibility is known broadly as patient empowerment, an outcome of giving patients more control over the decisions and actions affecting their health (Groen et al., 2015; Boveldt et al., 2014; Maunsell et al., 2014).

With the increased emphasis on responsibility and active involvement, patient empowerment has emerged as an important indicator of efficient healthcare and successful symptom management (Barr et al., 2015; Maunsell et al., 2014; Van Den Berg, Van Amstel, Ottevanger, Gielissen, & Prins, 2013; McCorkle et al., 2011). Yet surprisingly, empowerment as a social phenomenon is not well understood (Groen et al., 2015). Typically explored from the perspective of clinicians and researchers (Jerofke, 2013), our notions of empowerment is largely based on assumptions embedded in the ways we talk about illness (Sinding, 2014; Bell, 2012; Mathieson & Stam, 1995). Rhetoric associated with words such as “survivorship” and phrases like “fighting cancer” and “the war against cancer” dominate the media and the world of cancer and psychosocial oncology research (Ristovski-Slijepcevic & Bell, 2014; Bell, 2010; Sinding & Gray, 2005). Emerging from this rhetoric are trending research topics such as patient-activation (Hay et al., 2016), patient-engagement (Forbat, Cayless, Knighting, Cornwell & Kearney, 2009),

and self-management (McCorkle et al., 2011) that share a strong emphasis on individual control, responsibility and “empowerment” (Sinding, Miller, Hudak, Keller-Olaman, & Sussman, 2011). Nevertheless, of the empirical work that explores the ways in which survivors take responsibility and establish control in the face of an illness that causes physical and psychosocial suffering is very limited (Howell, Harth, Brown, Bennett, & Boyko, 2017; Hay et al., 2016; Paterson, Jones, Rattray, & Lauder, 2015). Consequently, my study purpose was to explore the notion of empowerment from the perspective of post-treatment cancer survivors. From this diagnosis forward, I wanted to gain a deeper understanding of empowerment in the context of the illness experience. In addition, my objective was to develop a substantive theory to postulate how empowerment can be used to address the gaps I have identified in cancer survivorship and rehabilitation.

## ***1.2 Cancer Survivorship and Rehabilitation***

### ***1.2.1 Physical and Psychosocial Impacts of Cancer***

Over the last four decades, Canada has experienced a drastic rise in cancer incidence due to an aging population and improvements in cancer detection. It is estimated that 206,200 new cases of cancer occurred in Canada in 2017 (Canadian Cancer Society’s Advisory Committee on Cancer Statistic, 2018). However, because of advances in cancer prevention, screening, and early detection and treatment, the number of Canadians dying from cancer has declined over the last two decades in most age groups. According to the Canadian Cancer Society, 62% of those diagnosed with cancer are expected to survive 5 years after diagnosis, which constitutes a substantial increase of 56% in survival rates from the decade between 1992-94 to 2004-06 (Canadian Cancer Society’s Advisory Committee on Cancer Statistic, 2009). These increases in

cancer survival have created a growing population of individuals surviving cancer whose quality of life is at risk due to the consequences of cancer and its treatment (Canadian Association of Psychosocial Oncology, 2010).

Cancer treatments such as chemotherapy, radiation and surgery are often invasive and can leave the body permanently altered and the psyche scarred. Changes in appearance, chronic pain and disability, sexual dysfunction, psychological distress, and depression constitute the wide range of such concerns. Consequently, cancer survivors face persistent practical and social problems such as financial concerns, reduced employment opportunities, stigmatization, and social and spiritual crisis (Turnbull Macdonald, et al., 2012; Canadian Association of Psychosocial Oncology [CAPO], 2010). These problems also span physical, informational, emotional, psychological, social, spiritual, and practical domains, imposing a tremendous burden on the lives of cancer survivors (Stanton, Rowland, & Ganz, 2015; Institute of Medicine [IOM], 2008).

Thus, as survival rates improve, it is apparent that those diagnosed and treated for cancer are increasingly living with a daunting array of consequences and side effects. Accordingly, the demands for integrated and interdisciplinary teams of healthcare providers have increased to try and meet the diverse physical and psychosocial needs of a growing population of cancer survivors (IOM, 2008; Hewitt, Greenfield, & Stovell, 2006). Cancer rehabilitation aims to address these needs with multi-disciplinary research and innovative practice (Weis & Giesler, 2014; Alfano, Ganz, Rowland &, Hahn, 2012).

### *1.2.2 Cancer Rehabilitation*

In 2005, the Institute of Medicine published a widely distributed report called 'From Cancer Patient to Cancer Survivor: Lost in Transition' (Hewitt et al., 2006). The authors emphasized the need to invest in more research to explore the post-treatment needs of cancer survivors. With increased cancer survivorship, cancer is now viewed as a chronic illness that needs continuing, long-term management and rehabilitative care (CAPO, 2010; Howell et al., 2009; McCabe & Jacobs, 2008; Otfinowski, Christian, Mackenzie, Handman, & Bultz, 2003). But prior to 2005, very little attention was devoted to the period following acute treatment. The wide distribution of the report gained international attention and was pivotal in the growth of 'cancer survivorship care', an area that specifically addresses the long term needs of cancer survivors.

'Cancer survivorship' can be defined in many ways (Ristovski-Slijepcevic, 2008, p. 5-7), but is most often understood as either the period following acute treatment (i.e. post-treatment) when the person has been disease free for a specific number of years or described more holistically as the period from the time of diagnosis, through the balance of life. Thus, a person can be called a cancer survivor the moment they are diagnosed or may only be deemed a survivor once they are medically defined as disease free. While discussions remain about the most appropriate definition of cancer survivorship (Feuerstein, 2007), I define cancer survivorship as the period from the time of diagnosis through the balance of life. This way of defining cancer survivorship was coined by the Live Strong Foundation (Shapiro et al., 2009) and reflects the various and lasting ways cancer can impact the individual. Emerging from this recognition are specific subspecialties of cancer care: supportive care; palliative care; end of life care; and rehabilitation.

Cancer rehabilitation focuses on supporting the growing population of cancer survivors living with any form of physical, psychological, or cognitive impairment caused by the diagnosis and treatment of cancer (Egan et al., 2013; Gilchrist et al., 2009). Such impairment commonly emerges from the disease process or its treatment, including the effects of surgery, chemotherapy, and radiation and if not addressed, can lead to participation restriction and functional limitations known as disabilities (Silver et al., 2015; Egan et al., 2013). Examples include reduced mental functioning (chemo-brain or “brain fog”) (Boykoff et al., 2009), altered appearance (Vickery et al., 2003), pain (Glare et al., 2014), mobility restrictions (Hidding et al., 2014), voice and speech impediments (Kraaijenga et al., 2016), and cardiovascular, respiratory (Dunger et al., 2015) and reproductive concerns (Gorman et al., 2015). These problems can reduce one’s ability to participate in work, leisure, self-care, and the capacity to be autonomous (Weis & Giesler, 2014). Survivors who encounter these types of participation restrictions often suffer distress and depression that contribute to other health-related concerns, thereby reducing the quality of life (Cheville et al., 2017; Silver et al., 2015; Silver, Baima, & Mayer, 2013). Yet, cancer rehabilitation has not consistently been integrated into routine clinical practice in Canada and the field remains relatively new and underdeveloped leaving many impairments not fully understood or addressed (McEwen et al., 2016; Egan et al., 2013; McEwen et al., 2013).

In Canada, cancer rehabilitation is itself in stages of development and flux (McEwen et al., 2016; Egan et al., 2013; McEwen et al., 2013; Jefford et al., 2013). With no national rehabilitation program for cancer of any type (Thomas-MacLean et al., 2009), care specific to improving functioning and reducing disability from a diagnosis of cancer and its treatments vary between institutional settings creating variability in services offered (see Tomasone et al., 2017). Gaps in service delivery include limited evidence and clinical expertise in detecting and treating

functional concerns related to the diagnosis and treatments for cancer (Cheville et al., 2017; Chasen, Feldstain, Gravelle, MacDonald, & Pereira, 2013; Alfano et al. 2012; Franklin et al. 2007). Furthermore, cancer rehabilitation is not typically seen as a unique specialty, but grouped with post-treatment palliative and/or supportive care (Crevenna, 2015; Chasen et al., 2013; Mcewen et al., 2013). Many scholars have noted that this amalgamation contributes to a growing confusion between what cancer rehabilitation involves and what palliative and supportive care provides (Silver et al., 2015; Alfano et al., 2012; Cheville, Kornblith, & Basford, 2011; Cheville & Tchou, 2007). For instance, a disability is not only caused by a physical condition, but also an outcome of constraining social, psychological and environmental characteristics that make participation in day-to-day activities more difficult. Yet, many post-treatment interventions focus on improving or managing physical symptoms as a way to address a disability with less attention devoted to identifying the multi-dimensional aspects associated with the inability to participate (Stout et al., 2016; Silver et al., 2013; Egan et al., 2013). This neglect is apparent in the current state of the literature that illustrates a very narrow focus on managing physical symptoms rather than exploring the functional ways survivors might adapt or incorporate their condition into daily living (Hunter, Gibson, Arbesman, & D'Amico 2017; Hunter, Gibson, Arbesman, & D'Amico 2017b; Salakari, Surakka, Nurminen, & Pylkkänen, 2015; Loh & Musa, 2015; Egan et al., 2013). A pressing issue emerging from the state of the evidence is the need for a model of cancer rehabilitation distinct from palliative and supportive care that focuses on functional over physical concerns and captures how survivors experience and adapt to the physical, social and environmental threats that contribute to disability.

Given the current state of evidence, many cancer survivors are at risk for disability, which imposes a significant burden on the individual as well as on the cancer care system. To

alleviate this burden, survivors have been asked to take a more active, collaborative and informed role in their care. In the literature, this transfer of responsibility is often referred to as patient empowerment (Maunsell et al., 2014; Jerofke, 2013; Bulsara et al., 2004; McCorkle et al., 2011).

### ***1.3 Our Present Understanding of Empowerment***

Empowerment has become a topical issue in cancer survivorship care and rehabilitation. Although subjective by nature and difficult to define (Tengland, 2008; Aujoulat, d'Hoore, & Deccache, 2007; Kuokkanen & Leino-Kilpi, 2000; Perkins & Zimmerman, 1995), empowerment is broadly seen as both a process and an outcome associated with regaining or taking control (Maunsell et al., 2014; Jerofke, 2013; Bulsara et al., 2013). More specifically, the phenomenon has been used to define the essence of human existence, adaptation and personal growth, but also aspects associated with organizational and community development (Aujoulat et al., 2007).

Historically, the word “empowerment” emerged during the political and economic shift towards sociocultural reform during the civil rights and women’s movement of the 1960s and the self-help movement of the 1980s in North America (Finfgeld, 2004). This emergence positions empowerment within two different overlapping social movements; one associated with social oppression and social action and the other with neoliberal political reform. Both movements imbue empowerment with meanings that describe shifts in social power around control and autonomy (Bravo et al., 2015; Anderson & Funnel, 2010; Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008).

By definition, empowerment is associated with the field of rehabilitation (Fisher & Howell, 2010). In rehabilitation, control and autonomy, or the lack thereof, refers to the loss or

inability to participate in daily activities resulting from impairment or disability (Weis & Giesler, 2014; Fisher & Howell, 2010). Regaining that sense of control and autonomy are key outcomes to the rehabilitation process. Yet, beyond this definition, the associated processes people employ are underexplored. For example, although research on empowerment is vast and encompasses theoretical, quantitative, qualitative and mixed methods research, definitions are limited to an anticipated outcome, such as self-management or self-efficacy, rather than defining empowerment according to its processes (Aujoulat et al., 2007). This lack of focus on the processes of empowerment creates two overlapping, fundamental gaps from the literature that impacts how it is applied in the rehabilitation of cancer survivors. The first gap relates to defining the processes of empowerment and the second is acknowledging the complexities of its processes.

First, even though empowerment is most commonly associated with control and autonomy, there is no agreed upon outline of its processes. Different theoretical orientations such as critical theory (Fulton, 1997), social/psychological theory (Shearer, 2009), organizational theory (Sarmiento, Laschinger, & Iwasiw, 2004) and post-structural theory (Foster-Fishman, Salem, Chibnall, Legler, & Yapchai, 1998) have varying views of the processes towards enhancing control and autonomy mitigating against a common integrated understanding of empowerment (Bradbury-Jones, Sambrook, & Irvine, 2008; Kuokkanen & Leino-Kilpi, 2001). Within critical theory for example, empowerment is understood as struggle for control and autonomy in circumstances of oppression. From this perspective, empowerment is equated with liberation (Fulton, 1997). In comparison, organizational theory sees empowerment as a phenomenon that emerges when control and autonomy is shared between people to achieve a common goal. A great deal of research from an organizational perspective has been based on the

Kanter's theory of structural power (Laschinger, 1996). This theory proposes four conditions for empowerment: opportunity for advancement; access to information; access to support; and access to resources (Bradbury-Jones et al., 2008). From this perspective, the processes of empowerment are based on the ability to perform certain tasks and actions successfully. This view of empowerment is different when compared to critical theory that defines empowerment as a struggle for freedom when one group is being oppressed by another. Yet, even with these differences there can also be overlap between these theoretical orientations. For example, Laschinger, Gilbert, Smith, & Leslie (2010) used a critical approach to apply Kantor's theory of empowerment to address political structures within medical institutions that are oppressive towards nurse practitioners. This type of overlap adds to the ambiguity concerning what is involved in the processes of empowerment. Is it a struggle for power between two or more groups or does it involve sharing power to accomplish specific organizational goals? Thus, without an integrated understanding that includes multiple perspectives of empowerment, this phenomenon remains difficult to apply in circumstances when each theory could contribute to a greater understanding of its processes.

Second, empowerment is considered a complex social phenomenon because it takes on different processes in different contexts. The essence of the experience is largely interpretive, based how people perceive, experience and address threats to autonomy with cultural and individual variations in what it means to be independent (Ryan & Deci, 2006; Kieffer 1984; Gibson 1991). For example, illness is often understood as a threat to autonomy. Yet, some cultures view certain illnesses differently and may perceive them to be less of a threat (see Navon, 1999). Therefore, it is reasonable to conclude that the processes of empowerment will vary depending on the perceptions of the individual. The resulting paradox, however, is that

empowerment is rarely explored from the perspective of the individual. Certainly this is true in the field of post-treatment cancer survivorship and rehabilitation, where empowerment has yet to be explored from the perspective of the survivors themselves (Jerofke, 2013). For example, in cancer survivorship and rehabilitation, notions of how to become empowered is largely based on assumptions (discourse) embedded in the popular ways we understand cancer survival. But, these assumptions are not always representative of the lived illness experience leaving empowerment a phenomenon that is still not fully understood.

#### ***1.4 Empowerment, Cancer Survivorship, and Rehabilitation***

In cancer survivorship and rehabilitation, empowerment has become an essential concept to understand. Conveying meaning associated with the loss of control (Maunsell et al., 2014; Bulsara, Styles, Ward, & Bulsara, 2006) and the lack of infrastructure to support the diverse needs of survivors, empowerment describes the processes and outcome associated with self-management (McCorkle et al., 2011). But what we know about these processes and outcomes is largely based on assumptions embedded in the popular ways we understand the illness experience. This discourse reflects the reality that a diagnosis of cancer is no longer a death sentence, but the discourse is also problematic as it suggests that cancer is an illness people can survive if they have the strength and the means to stand up and take control. This type of rhetoric dominates the media and cancer (psychosocial) research (Ristovski-Slijepcevic & Bell, 2014; Bell, 2010; Sinding & Gray, 2005). Topics such as patient-activation (van Maarschalkerweerd, Rademakers, & Rijken, 2017), patient-engagement (French et al., 2015), and self-management (Howell et al., 2017) that place a strong emphasis on individual control, responsibility and “empowerment” dominate the field (Sinding et al., 2011). Yet, there is very little empirical

research that explores and assesses the ways in which survivors become empowered in the face of an illness that causes both physical and psychosocial disability and suffering (Egan et al., 2013).

In the current research, empowerment is typically explored using theories of social psychology that position it as a process and outcome associated with increased collaboration and more effective communication between survivors and healthcare providers. It is believed that by cultivating this type of relationship, survivors will feel more in control and capable of adopting behaviours to survive cancer (Maunsell et al., 2014; Kaur, 2014; Bulsara, 2008; Epstein & Street, 2007). This research uses self-efficacy as a core construct of the empowerment process (Barr et al., 2015). However, this literature is mainly deductive with little empirical data grounded in the perspectives and experiences of cancer survivors (Jerofke, 2013).

Of the small number of studies that have alluded to empowerment from the perspective of survivors, the concept is described as going beyond the idea of self-efficacy to work with what resources survivors have to achieve optimal quality of life (Stang & Mittelmark, 2008; Bulsara et al., 2004; Mok, 2001). Quality of life in this case did not always include increased survival prognosis even when survivors expressed a satisfactory level of control or mastery in the management of their condition. These studies are however limited in depth and scope because of theoretical and methodological weaknesses. For instance, when exploring the meaning of empowerment, Mok (2001) only considered the perspective of 12 Chinese cancer patients limiting the transferability of their findings to other populations.

Given the paucity of empirical research, the purpose of this doctoral study was to explore the notion of empowerment from the perspective of post-treatment cancer survivors. The aim

was to illuminate how an empowering experience may be constructed throughout the cancer trajectory and to postulate the related implications for cancer survivorship and rehabilitation.

### *1.5 The Present Study*

The purpose of this doctoral study is twofold: first, to advance understanding of empowerment using the specific theoretical lens of social constructivism, which is not limited by a priori assumptions inherent in other theoretical traditions. It is a lens that allows different interpretations of the empowerment phenomenon to be compared and contrasted, contributing to an integrated theory that incorporates multiple ways of understanding this phenomenon. Second, the driving force of this study is to make apparent the processes of empowerment using the qualitative method of grounded theory to allow construction of a substantive theory based on the experiences of post-treatment cancer survivors. The dual purposes of this study yield a more comprehensive understanding of a phenomenon that in current science or care provision is not well understood, but integral to the field of cancer rehabilitation. This research provides a theoretical framework that describes a common set of actions that speaks to how survivors participate and engage in their lives amidst experiences of disability and the long-term effects of treatment. Research on empowerment may therefore contribute to the development of more comprehensive cancer rehabilitation programs.

#### *1.5.1 Research Questions and Objectives*

The primary and secondary research questions for this study are:

##### *Primary research question*

- In what ways do cancer survivors define, describe and/or experience the processes of empowerment?

*Secondary research questions:*

- How do cancer survivors describe the emergence of empowerment within various contexts and relationship related to their illness? (i.e., how does empowerment emerge in relation to establishing control over aspects of their illness and/or life as they interact with their care providers, family members and other parts of their social environment?)
- What are the connections and relationships between processes of empowerment, patient engagement and education, care planning, decision-making, and self-management from the perspective of survivors?

By exploring these questions, I have built a theoretical framework to:

1. Define empowerment using the meanings, experiences and perceptions of cancer survivors
2. Explore how cancer survivors experience this social phenomenon
3. Elaborate on the characteristics of the experience in relation to commonly held assumptions and beliefs about cancer
4. Inform the role of empowerment in the post-treatment management and rehabilitation of cancer survivors

*1.5.2 Research Design*

To explore how cancer survivors define and experience empowerment, I used a qualitative research design guided by the principles of social constructivism drawing on the constructivist grounded theory method informed by the work of Kathy Charmaz (2014). Social constructivism is an interpretive lens that focuses on describing and understanding how meanings and actions are shaped by the interaction between the individual, their social world and the researcher. In social constructivism, the researcher is not seen as an objective observer, but an active participant in a co-creation of meaning (Creswell, 2013; Charmaz, 2014; Mills, Bonner, & Francis, 2006).

Constructivist grounded theory is an inductive form of research used to construct theories about social phenomenon that can be used to establish quantitative, mixed methods and qualitative research that seeks to understand human behaviour (Charmaz, 2014). Research methods for constructivist grounded theory rely on open-ended or semi-structured interviews and sampling strategies (purposeful and theoretical sampling) that follow an iterative process called constant comparative analysis. Constant comparative analysis involves collecting and analyzing data simultaneously and using findings to drive the process of inquiry forward. Through this process, Charmaz instructs researchers to use themes and categories that emerge from the data to determine the next stages in the data collection process (for instance, whom to interview next and what questions to ask them). The constant comparative method continues until little more is being learned about each theme or category, a point known as theoretical saturation (Mitchell, 2014; Charmaz, 2014; Boeije, 2002). The idea is that once saturation is reached, the data collection can stop and the theoretical design can start to be recognized leading to the establishment of a substantive theory.

To build a substantive theory of empowerment using the grounded theory methodology, I purposely sampled 22 cancer survivors (cancer of the head or neck and or breast) and conducted one semi-structured interview per participant. Interviews explored participants' illness experiences and views of empowerment. In my analysis, I used the constant comparative method and theoretical sampling to identify the most salient themes and categories to map the empowerment process.

### *1.5.3 Study Population and Rehabilitation*

Post-treatment head and neck (head/neck) and breast cancer survivors were recruited to explore the meanings and processes of empowerment from their own perspectives. Head/neck and breast cancer are two types of cancer that present different social characteristics, a consideration for how empowerment is defined and experienced.

Head and neck cancer (cancer of the tongue, mouth, and throat - larynx and oral cavity) accounts for approximately 3% of all new malignancies in Canada, while breast cancer ranks among the top four most common cancers, accounting for approximately 26% of new malignancies (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Although head/neck and breast cancer have different causes, risk factors, treatments and physical consequences from treatments (Binkley et al., 2012; Molassiotis & Rogers, 2012; McQuestion, Fitch, & Howell, 2011; Tighe, Molassiotis, Morris, & Richardson, 2011), they present similar but varying degrees of psychosocial challenges associated with changes in appearance, altered physical abilities, pain, fatigue, social isolation, a reduced sense of self, and eroding social relationships (Lang, France, Williams, Humphris & Wells, 2013; Denieffe & Gooney, 2011). For example, head/neck cancer treatments are associated with a range of debilitating side effects including difficulties with eating, swallowing, breathing, and speech, in addition to an altered appearance. These side effects can reduce a person's ability to communicate and converse and build relationships with others (Howren, Christensen, Karnell, & Funk, 2013; List & Bilir, 2004). Breast cancer treatments bear a different range of debilitating side effects, such as mobility restrictions around lymphedema, neuropathy and chronic pain and psychological and social concerns around altered sexual functioning and identity (Fallowfield & Jenkins, 2015; Thomas-MacLean et al., 2009; Cormier et al., 2010; Hewitt, Herdman, & Holland, 2004).

While specific effects are somewhat varied, both groups of cancer survivors suffer from an altered appearance, changes in social relationships, and high levels of symptomatology. Taken together, these effects can have a wide ranging social impact. Permanent changes in self-image, social stigma, isolation and alienation are common experiences among head/neck and breast cancer survivors (Richardson, Morton, & Broadbent, 2015; Lang et al., 2013; Hewitt et al., 2004). However, given the difference of incidence rates, head/neck cancer does not receive the same level of support, advocacy or funding for research and program development, which leaves survivors of this cancer, their clinicians and rehabilitation specialists, with fewer evidence based practices and resources for post-treatment and rehabilitative care (De Felice, Musio, & Tombolini, 2015; Howren & Christensen, 2013).

Since empowerment is an experience that is embedded in the social characteristics of an illness and the perceptions of the individual, there is a possibility that these differences in disease features and levels of support may cause variations in the meanings and processes of empowerment as perceived by those who are afflicted. For example, compared to breast cancer, there is a paucity in available rehabilitation services for head/neck cancer. Breast cancer rehabilitation includes a combination of pharmaceutical, surgical (breast re-construction), physical and psycho-educational interventions to address concerns about body image, pain, physical mobility and range of motion and cognition (Loh & Musa, 2015; Harris, Schmitz, Campbell, & McNeely, 2012). Evidence based practice for exercise and physical rehabilitation, psychosocial support, nutritional and lifestyle interventions, as well as alternative rehabilitation such as yoga and music therapy, are available in the breast cancer population (Gokal et al., 2015; Testa, Iannace, & Di Libero, 2013; Gudenkauf et al., 2015; Minton & Jane, 2015; Morrison & Thomas, 2015; Loh, Yip, Packer, & Quek, 2010). These same types of interventions tailored

specifically for those with head/neck cancer are not as readily available thereby creating an uneven distribution of rehabilitation practices and quality care (McEwen et al., 2016).

Rehabilitation from head/neck cancer includes reconstructive surgery and the reliance on assistive devices and different types of physical therapy to regain function. For example, those with cancer in the interior of the mouth and nasal cavity require surgical reconstruction to help people regain their ability to eat. However, such reconstructions have severe consequences such as xerostomia (dry mouth) and hygiene related issues causing further problems (Nagy et al., 2014). In addition, tumors of the tongue or floor of the mouth often necessitate mandibular resection, resulting in serious disabilities, including impairments of chewing, swallowing and speech, drooling and facial anomalies. To address these consequences, rehabilitation also involves speech language pathology, the use of assistive devices to eat and speak, and psychosocial support to acclimatize to altered appearances (Semple et al., 2013). In addition to differences in available services, head/neck cancer is linked to alcohol consumption, tobacco use, lower socio economic status and more recently to the human papilloma virus (HPV). These connections place people with head/neck cancer at risk of being stigmatized for developing a “self-inflicted” disease (Lebel et al., 2013). In contrast, breast cancer survivors receive much more support and advocacy to counter possible stigma associated with their diagnosis (Marlow, Waller, & Wardle, 2015; Weiss, Stephenson, Edwards, Rigney, & Copeland, 2014; Carter & Nguyen, 2012). Risk factors for breast cancer are multi-dimensional and include a combination of family history, ancestry, environmental risks and life-style behaviours associated with poor diet and obesity, but tend to occur in high-income populations (DeSantis et al., 2014). Thus, exploring empowerment in two groups that present these differences may produce a richer understanding of a social phenomenon that could be applicable across all cancers. Therefore, I

chose to purposely sample participants with these cancers to determine if any nuance exists in the ways empowerment is described.

#### *1.5.4 Summary of Data Collection and Analysis*

Purposeful sampling was used to identify English speaking non-metastatic adult head/neck and breast cancer survivors within 3 months to 5 years post-treatment. Participants were recruited from the head/neck and breast cancer outpatient clinics at the Princess Margaret Cancer Centre (PM) at the University Health Network (UHN) in Toronto, Canada. Semi-structured one on one interviews served as the primary means of data collection in addition to field notes based on observations from interviews. Interviews explored participants' illness experiences and views of empowerment. Interviews were recorded and transcribed verbatim noting punctuation and pauses. Data analysis relied on the constant comparative method, three levels of data coding (initial, focused and theoretical coding) and theoretical sampling to categorize and map the empowerment process (Charmaz, 2014). Theoretical sampling was applied by using my knowledge of the literature and insights from participant interviews to identify and theorize which emerging themes from the data were more prominent to the empowerment process. To evaluate emerging theories and themes, I used each subsequent interview to confirm or disconfirm these insights. This inductive/deductive process is inherent in constructivist grounded theory method. Theoretical sampling combined with the constant comparative method (abductive reasoning) allowed me to build a substantive theory of the empowerment process grounded in the experiences and perspectives of those that I interviewed. Using these data collection and analysis techniques, I conducted and interpreted semi-structured

interviews with 22 post-treatment head and neck (head/neck) and breast cancer survivors to explore the meanings, experiences and processes of empowerment while living with cancer.

#### *1.5.5 Summary of Findings*

Empowerment is a dynamic and conflicting phenomenon that emerged from the struggles associated with each person's illness experience. From this struggle, empowerment occurred in two different and paradoxical ways: 1) Successfully taking control over the impact of the illness as a mean to circumvent an eroding and changing self, and 2), a process of relinquishing control over aspects of the illness deemed irrepressible and incorporating those aspects into a new identity.

#### *1.5.6 The Researcher*

My interest in empowerment arose when I first began working in cancer survivorship care in 2010. Soon after receiving my Masters of Arts degree in communication in 2009, I was hired by a non-profit grass roots organization called Prevent Cancer Now. In partnership with the Ottawa Regional Cancer Foundation, I was responsible for developing evidence based material and knowledge translation strategies to promote healthy behaviours reducing the risk of a cancer diagnosis. Coming from an arts based and non-clinical background, this project introduced me to the field of cancer survivorship.

After the project was completed in 2011, I was hired by the Ottawa Regional Cancer Foundation. As a member of the program development team, I played a foundational role in their development of the MapleSoft Centre for Cancer Survivorship, a place for quiet refuge, support and empowerment to cancer patients and their families in the Eastern Ontario area. Here, I was

introduced to the concept of empowerment as a fundamental health related concept in the treatment and management of cancer.

Once introduced to the concept, I realized that empowerment has had a significant meaning in my upbringing. Growing up suffering from chronic anxiety, I have always been plagued by issues related to control and uncertainty. Situations and social environments that brought a sense of the unknown provoked feelings of anxiety and ensuing panic attacks that could be debilitating. There were moments in elementary school for example when a panic attack would occur. If it happened during class time, I was removed from my seat and placed in the corner of the room until the panic attack subsided. I presume this would occur because I was being a disruption to the class although it felt more like a punishment. What made these situations particularly difficult is that I was in plain view for all my classmates to see. I was often ridiculed and bullied by classmates. As a result, these panic attacks created concerns around my ability to learn and excel socially and academically. I had very little control over these situations and it was a gradual process of learning to adapt, cope and take control or work with the anxiety in order to excel. Therefore is it almost ironic that I found myself in a situation to explore empowerment, albeit within the context of cancer survivorship, for it plays a significant role in the construction of my own sense of self.

Denzin and Lincoln (2005) note that it is vital that researchers explicitly state their own beliefs, feelings and epistemology in connection with the world they are researching. The purpose of such disclosure is to position the researcher for the reader. This positioning is vital to interpretive qualitative research in particular, given the need to disclose its inherent subjectivity in order to stay true to the stories of research participants. In other words, the findings of interpretive qualitative research must represent the people being studied and not the researcher.

Since empowerment is a personally meaningful concept in my own life, I defined it for myself before I began data collection. On December 3<sup>rd</sup>, 2015, I defined empowerment as:

...finding a balance between trying to fight for control and letting go of control. It's a very fluid process. There are times when trying to fight for control makes you feel less in control and therefore more disempowered where at other times gaining control makes you feel on top of the world. It's about balance.... it's also about fighting the societal pressures of where and in what ways I should do things. If people tell me I should do this or do that, control this and control that... and if it did not fit my own beliefs or ideals, then I need to fight these popular notions so I can experience and do the things in a way that fits best with who I am. By resisting these popular notions, I empower myself... but at the other end, I also feel that resisting these popular notions can be isolating. So where is the middle ground between control... letting control go and going with the flow?

I have kept this definition in mind as I collected, analyzed and reflected on my emergent findings to ensure I maintain an awareness of my own potential biases to accurately interpret the meanings and perspectives of my participants.

In terms of epistemology, I believe that illness is an experience embedded with cultural and social meaning making illness a partially constructed phenomenon (Conrad & Barker, 2010). This suggests that definitions of illness can vary depending on the cultural and social interpretations of what constitutes a threat to well-being. Not only do these interpretations shape how individuals come to understand and live with this threat, but generate the knowledge needed to treat the illness. This epistemology is complementary with the philosophies of social constructivism and symbolic interactionism that position reality as knowledge that is shaped by individuals' social interactions, subjective interpretations and shared meanings of the social world in which they live (Charmaz, 2014; Creswell, 2013).

Consistent with these philosophies, I do not regard myself as an objective observer as a researcher, but rather as an active participant and co-creator of meaning with my research participants. This means that my own experiences and sense of individuality impacts how I interpret and assign meaning to the experiences of those I explore. Thus, even though I have no

formal clinical training, I am approaching the topic of empowerment within the lens of rehabilitation sciences. Additionally, my course work and experiences as a volunteer at the Ottawa Hospital Cancer Centre and research trainee at the Princess Margaret Cancer Centre together impact how I interpret and assign meaning to the experiences of those I explore. In order to become aware, and acknowledge, these influences, I use the rigour built into the constructivist grounded theory method, continuously comparing my interpretations of the data with the meanings that participants assign to their experiences. It is a process accomplished through the iterative inductive/deductive design of grounded theory, assisted by keeping an audit trail, a reflexive journal, and memo writing.

### ***1.6 Dissertation Overview***

This dissertation follows the ‘traditional format’ that provides a systematic account of my doctoral research. What follows this introductory chapter is a literature review (Chapter 2) that expands on the ideas already presented. I conclude Chapter 2 by introducing my primary and secondary research questions of this dissertation. In Chapter 3, I provide a detailed account of the methodology I used to explore my research questions. My findings are presented in Chapter 4 and I conclude this dissertation with Chapter 5, the discussion of my findings and their relevance to the field of cancer survivorship and rehabilitation. Following Chapter 5 are the references and appendices associated with this work.

## **Chapter 2**

### **Literature Review**

#### ***2.1 Introduction***

In cancer care, the post-treatment survivorship phase of the cancer continuum is characterized by a decrease of professional and social support and requires patients to become active and informed participants in managing their own care and learning how to address their own needs (McCorkle et al., 2011; IOM, 2005). However, as a result of long term persistent and often unpredictable physical and psychosocial sequelae from a diagnosis of cancer and its treatments, cancer is often described as an illness where survivors experience a loss of control and autonomy over their health and life (Bulsara et al., 2004). This loss of control and autonomy presents many challenges to adopt effective coping, behavioural and self-management strategies (Maunsell et al., 2014; Fitch, 2008; Mishel et al., 2005). Additionally, this has created much interest in the concept of empowerment, its processes of re-establishing control and autonomy, and its clinical application in cancer survivorship and rehabilitation (Groen et al., 2015; Jerofke et al., 2013). However, there are gaps in both theory and evidence based practice around understanding the ways in which survivors attempt to re-establish control over their life when a diagnosis of cancer can be disabling in so many ways (McCaughan & McKenna, 2007). This chapter outlines these missing features of knowledge and provides the rationale as to why it is essential to explore empowerment as a fundamental concept in the treatment and rehabilitation from a diagnosis of cancer.

## ***2.2 Cancer Survivorship***

### *2.2.1 Defining Cancer Survivorship*

In the field of cancer research, definitions of survivorship have ranged broadly from the original use of the term that described a cancer survivor as a family member who died from cancer to anyone directly impacted by cancer including family members and caregivers (Doll, Kazanjian, Smillie, Ward, & Chasen, 2012; Ristovski-Slijepcevic, 2008; Feuerstein, 2007). For the purpose of this research, I will be using the definition of cancer survivor that refers to the individual diagnosed with cancer from the time they are diagnosed, through the period of their treatment, and continuing for the rest of their life. This definition, coined by the Live Strong Foundation (formerly known as the Lance Armstrong Foundation), was chosen to reflect the growing body of evidence that cancer is no longer viewed as an acute illness associated with mortality, but rather a chronic illness with many long-term side effects (Stanton et al., 2015; McCorkle et al., 2011; Phillips & Currow, 2010).

### *2.2.2 The History of 'Cancer Survivorship'*

Although the cancer survivor label has today become widely used, the term itself is relatively recent, generally attributed to Fitzhugh Mullan (Ristovski-Slijepcevic & Bell, 2014). As both a physician and a cancer survivor himself, Mullan wrote and published an influential commentary in the *New England Journal of Medicine* in 1985 arguing against the dominant view that there were two different paths for people diagnosed with cancer: either death or cure. Instead, he suggested a third path of survival characterized by dealing with the physical, psychological, and social effects of diagnosis and treatment (Mullan, 1985). Mullan's landmark

piece had a snowball effect and shortly after his article was published, a number of initiatives emerged that dramatically increased the profile of cancer survivorship. In 1986, the National Coalition for Cancer Survivorship was established. This was instrumental in the development of an Office of Cancer Survivorship within the National Cancer Institute a decade later, the aim of which was to change public perception of cancer so that it could be viewed as a treatable illness. A similar paradigm shift has also occurred in Canada (see Fitch et al., 2009). This shift in perception from individuals with cancer as victims towards individuals as survivors created new ways of understanding cancer. This transformed understanding has dramatically magnified the profile of cancer survivorship.

### *2.2.3 “Cancer Survivorship” as a Dominant Discourse*

Stories of cancer survivorship appear everywhere. The topic features prominently in print and electronic media, with celebrity survivors speaking about their experiences of enduring and surviving the illness (Sabel & Cin, 2016). Stories also appear through corporate and non-profit fundraising initiatives designed to support peers and colleagues touched by this illness (Geiger, Strom, Demark-Wahnefried, & Buist, 2008). And finally, the topic features conspicuously in many oncology journals in all of the major subfields (oncology nursing, clinical oncology, psychosocial oncology, and so forth), and comprises a key focus for dedicated research and conference proceedings (Ristovski-Slijepcevic & Bell, 2014). In all, these areas of prominence have contributed to specific cancer survivorship discourses (Ristovski-Slijepcevic & Bell, 2014; Rowland & Bellizzi, 2008).

A cancer survivor is most often represented in the media as a triumphant individual who overcame adversity and death by braving the hardships associated with a diagnosis of cancer and

its treatments (McGannon, Berry, Rodgers, & Spence, 2016; Ristovski-Slijepcevic & Bell, 2014; Bell, 2012). This notion of a cancer survivor presents a narrative of the illness experience that tells a story of a relentless fighter who had the strength to overcome the daunting aspects of the illness and its treatment. This person is viewed as someone who took control, capable of being involved, informed and proactive in their care. As such, these are the characteristics that are implied in what it means to be diagnosed, treated, and to survive cancer.

As a dominant discourse, these characteristics heavily impact public perception of what cancer is and the ways in which people must behave in order to survive the illness (Smith, Klassen, Coa, & Hannum, 2016; Conrad & Barker, 2010; Thorne & Murray, 2000). Discourse in this context refers to a formal way of thinking that is influenced by the manner in which ideas seen as relevant to the overarching concept (survivorship) are constructed and expressed (Conrad & Barker, 2010; Kaiser, 2008). Using survivorship as an overarching concept to describe those diagnosed and acquiring treatment for cancer conveys specific meanings associated with enduring and surviving the illness. In this case, the notion of empowerment has emerged as the dominant way of understanding the cancer experience and forms the basis for knowledge generation and evidence informed practice in cancer care.

For instance, taking control and being involved in one's own health has emerged in policies associated with patient-centred care that govern cancer care and psychosocial oncology in Canada (Howell et al., 2016; Bidy et al., 2015). Accordingly, patient-activation, patient-engagement, patient-responsibility, self-management, shared decision making (SDM), have become the essential elements of what is considered to be quality cancer care, reflecting the emphasis on individual responsibility as the foci, and empowerment as the outcome, all of this within the influence of survivorship discourse (Hay et al., 2016; Reyna, Nelson, Han, & Pignone,

2015; Zucca, Sanson-Fisher, Waller, & Carey, 2014; McCorkle et al., 2011; Pulvirenti, Mcmillan, & Lawn, 2014).

Yet, there are a number of scholars who have challenged these deeply embedded assumptions (e.g., Bell, 2014; Ristovski-Slijepcevic & Bell, 2014; Khan, Rose, & Evans, 2012; Kaiser, 2008; Sinding & Gray, 2005; Fox, Ward, & O'Rourke, 2005). For example, Sinding et al. (2012) argue that the emphasis on patient-involvement as an essential element of quality cancer care rests on assumptions that people want to be in control and involved in their own healthcare. In actuality, studies exploring patient participation preferences accentuate a range of differences in the desire for involvement along a spectrum from active to passive (Lovell et al., 2014; Ernst et al., 2013; Thorne et al., 2013; Swainston, Campbell, Van Wersch & Durning, 2012). Furthermore, it seems to be the case that those who choose a more passive role are sometimes seen as “bad patients” who are non-compliant, in denial of their diagnosis, weak in character or even lacking a desire to survive (Steinberg, 2015). Steinberg (2015), in her article ‘The Bad Patient: Estranged Subjects of the Cancer Culture’, states the following:

...the bad patient, she who might not be interested in marching forward (or be able to do so), who might not be invested in life at any cost, or perhaps even at all, she who is ‘not brave’ – and indeed, what does a ‘not brave’ cancer patient look like?

(21)

This quotation emphasizes that a bad patient might simply be an individual who does not behave according to the empowerment narrative that dominates the cancer survivorship discourse. These individuals may manage their illness in other less apparent ways.

Ironically, there is a large body of work that explores the management behaviours of cancer survivors. However, according to the most recent systematic reviews, this research lacks rigour to explore any nuance regarding how people might understand, incorporate, and engage in

their care once they are diagnosed with cancer (Derksen, Bours, Mols, & Weijenberg, 2017; Howell et al., 2017; McCorkle et al., 2011). For example, there is an emerging body of literature distinguished by growing disdain towards the very label of ‘cancer survivor’ (Khan, Harrison, Rose, Ward, & Evans, 2012; Park, Zlateva, & Blank, 2009). In a qualitative study from the United Kingdom, Khan et al., (2012) asked 40 persons at least 5 years after the diagnosis of breast, colorectal or prostate cancer if they considered themselves to be cancer survivors. The majority did not endorse the term. To them, being called a ‘survivor’ implied a high risk of death and made them feel bound to an identity that did not describe their experience (see also Song et al., 2012).

However, other research findings suggest that some people gravitate towards the survivor identity. For instance, Deimling, Bowman, & Wagner (2007) found most older adults who have survived cancer for at least 5 years identify as cancer survivors and/or as ex-patients rather than as victims or patients. These differences in self-identification preferences reflect a range of how people internalize the illness experience and may pose differences across age, culture and gender. Hay et al., 2016 for example show that cancer is understood in distinctive ways for people who speak different languages. Yet “survivorship” continues to be used as the basis for cancer care research and policy development in Canada.

Given the many contradictions between the discourse and the individual illness experience, there are questions about the authenticity of empowerment narratives. On the one hand, empowerment refers to the importance placed on giving individuals more control in their treatment and recovery, but on the other hand, the dominance of this narrative ignores crucial variations reported in the illness experience. Therefore, I would argue that more attention must be placed on understanding the implicit and explicit meanings of empowerment, given the

pervasive influence of the empowerment narrative on knowledge generation and evidence informed practice in cancer care.

## ***2.3 Empowerment***

### *2.3.1 Search Protocol*

With the support of a professional librarian, a broad literature review (Grant & Booth, 2009) was conducted to develop an understanding of the concept of empowerment and its application to the field of cancer survivorship and rehabilitation. Relevant articles were identified by searching PsychInfo, CINAHL, PubMed and Google Scholar using the following to guide the review: empowerment, enablement, self-efficacy, and control. Concepts linked to empowerment such as self-actualization, health behaviour change, social cognitive theory, behaviorism, positive psychology, hope, uncertainty, distress, grief, resiliency, and mindfulness were also used. Articles were selected based on their level of application to the topics of cancer survivorship and rehabilitation. Key authors and studies were identified and included review papers such as concept analysis, scoping reviews and systematic review. My reading of the literature was organized into the sub-sections below: 1) Defining Empowerment; 2) The Historical and Theoretical Context of Empowerment; 3) Studying Empowerment; and 4) Challenges of Exploring Empowerment.

### *2.3.2 Defining Empowerment*

Empowerment has gained prominence as a central focus for healthcare in the move away from paternalism towards more equitable and collaborative models of healthcare delivery (Bravo

et al., 2015; McAllister, Dunn, Payne, Davies, & Todd, 2012; Herbert, Gagnon, Rennick, & O'Loughlin, 2009). As a process designed to facilitate self-management by developing better patient education and communication between patients with their clinicians (Anderson & Funnell, 2010), the ideal of empowerment is used as a method to improve the cost effectiveness of healthcare, especially for people affected by long term conditions (Bravo et al., 2015).

With increased attention on individual responsibility as the core constituent, empowerment has emerged as an important, but contested health related concept. Broadly, empowerment is a process and outcome associated with establishing control and mastery over a situation (Rappaport, 1987). However, the term is used interchangeably with other health related concepts such as patient-activation, patient-engagement, self-management and personal autonomy and distinctions are not clear, leading to a high degree of ambiguity (Jerofke, 2013; Aujoulat et al., 2007; Ryles, 1999). For example, empowerment can refer to enhancing ability to manage and control an illness: “empowerment is a social process of recognising, promoting and enhancing people’s abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives” (Gibson, 1991, p. 359). Empowerment may also describe “a helping process, a partnership valuing self and others, mutual decision-making, and freedom to make choices and accept responsibility” (Rodwell, 1996, p. 305). Finally, empowerment may simply portray a process of change determined by an individual’s desire to survive, as defined by Aujoulat et al : “empowerment is a complex experience of personal change guided by the principle of self-determination and personal growth...” (2007, p. 18 ). While there are important nuances of difference in these definitions, they share features related to establishing control and autonomy while differing in how this is done; a degree of ambiguity is the result.

Given this ambiguity, many scholars have argued over the various meanings attached to empowerment (Cyril, Smith, & Renzaho, 2015; Powers, 2003; Perkins & Zimmerman, 1995; Rissel, 1994). Powers (2003) argues that in healthcare, empowerment is often viewed as an intervention to produce compliance while ignoring the core constituents of what the word represents as a signifier of increasing autonomy. Notwithstanding these quarrels, empowerment continues to be applied in areas related to improving health equity and access (Rifkin, 2003), organizational structure and clinical work flow (Hawks, 1992), health promotion (Rissel, 1994), patient-engagement (McCarley, 2009), and the illness experience (Crossley, 1998). Even so, empowerment remains a problematic concept because there is no agreed upon understanding of what it entails.

Because of the range of meanings associated with empowerment, scholars have employed the concept analysis approach to gain a better understanding (Fotoukian et al., 2014; Jerofke, 2013; McCarthy & Freeman, 2008; Aujoulat et al., 2007). Concept analyses are a research method to clarify meanings of concepts that are widely used but poorly defined. Using approaches similar to scoping reviews, concept analyses synthesize the literature. The concept is then re-defined using the most common attributes (the defining characteristics), antecedents (events occurring prior) and consequences (outcomes) found through the synthesis (Risjord, 2009; Walker & Advant, 2005).

Findings from these analyses illustrate that it is hard to classify which characteristics are antecedents, attributes or outcomes since they appear to overlap. For example, antecedents include the desire for personal growth (Shearer, 2009), yet personal growth may also be considered an attribute as well as outcome of empowerment. Regardless of such cautions, these analyses illustrate that empowerment is most often conceptualized as a dynamic social process of

intrapersonal and interpersonal interactions that together form an empowering experience. As an intrapersonal interaction, empowerment is considered to be an individual psychological process of transformation. In addition, empowerment is considered a social process of knowledge exchange, shared values and shared responsibility from the interpersonal point of view and is facilitated by creating caring, trustful and non-judgemental environments. Thus, intrapersonal and interpersonal interactions together can be understood as different but dynamic and interdependent. Such features suggest that empowerment is social and psychological in nature, making it an essentially relational concept, which means it is culturally embedded, socially defined, and emergent when individuals interact and interpret their social world (Christens, 2012).

Foster-Fishman et al. (1998) argues that it is this dynamism that requires scrutiny of empowerment as a socially constructed concept with multiple meanings and pathways that vary across time depending on the individual and the context. Taking a constructivist paradigm using phenomenological inquiry and thematic content analysis, Foster-Fishman et al. conducted unstructured interviews with 49 employees from a large human service delivery organization to explore the various meanings of empowerment and how it manifests itself in this specific context. Six distinct dynamic pathways to employee empowerment were discovered: (a) having opportunities for job autonomy; (b) having the freedom to be creative; (c) gaining job relevant knowledge; (d) feeling trusted and respected; (e), experiencing job fulfillment; and (f) participating in decision-making. While the employees' experiences of empowerment could be categorized into these six pathways, Foster-Fishman et al. (1998) notes that the actual processes that constituted these experiences varied depending on how each employee chose to exercise their autonomy. For example, although most employees cited job autonomy as an important

component of their empowerment, some employees experienced job autonomy through their ability to regulate their schedule while others felt autonomous when they were able to make independent decisions regarding the content of their work. This variety was captured because Foster-Fishman et al. (1998) used methods that were capable of capturing this variety. Yet, very few studies have employed methods similar to Foster-Fishman et al. (1998) to capture this type of complexity, which certainly holds true to the concept analysis.

While concept analysis can be illuminating, it is not without its limitations. It has been demonstrated that concept analysis lacks the rigour when compared to other types of reviews such as scoping and systematic reviews and meta-synthesis (Draper, 2014; Beckwith, Dickinson, & Kendall, 2008; Botes, 2002). For example, not all concept analyses are transparent about inclusion and exclusion criteria and very few seek to appraise the literature they include. Given the limitations of concept analysis, and the relatively few rigorous scholarly investigations, the meaning of empowerment continues to stump scholars. Jerofke (2013), in her concept analysis of empowerment in cancer survivorship, is quite poignant when she notes that "... most of the empowerment literature in the context of cancer survivorship is written from the perspective of the healthcare provider and fails to recognize how survivors define empowerment"(p. 158). From her perspective, empowerment is a complex multi-layered concept that needs to be explored from the survivor's perspective. Yet, up until this point, survivors' perspectives are lacking.

### *2.3.3 Historical and Theoretical Context of Empowerment*

The historical and theoretical foundations of empowerment can provide some context to its widespread use in healthcare. Historically, the concept of empowerment first emerged during a political and economic shift towards sociocultural reform during the civil rights and women's

movement of the 1960s, and the self-help movement of the 1980s (Peck, 2013; Pulvirenti et al., 2014; Thibeault & Hébert, 2010). Derived from critical social theory (Anderson, 1996) and rooted in social action ideology (Aujoulat et al., 2007; Williams, Labonte, & Brien, 2003), empowerment describes the processes and outcomes associated with addressing any form of oppression by increasing individual or collective power, control, participation and responsibility over needs, wants and desires.

The shift towards neoliberalism is particularly relevant to understanding empowerment and the ways in which we understand illness as well as the means by which we access healthcare. In the 1960s, neoliberalism (Hall, 2011; Harvey, 2005) introduced fundamental changes to health policy rhetoric around reducing government spending on healthcare, increasing reliance on private and community partners to drive healthcare research and innovation, and shifting the role of the individual from passive recipient to an active consumer of health and wellness (Ellis, 2014; McGregor, 2001). Through neoliberal reform for example, it is believed that by shifting the responsibility away from the government to the individual and community, people will have more control over their health and increased access to health services at a reduced cost to the overall healthcare system. Although such a belief is highly controversial, especially in Canada where access to healthcare falls between a privatized and universal system, these philosophies of neoliberalism govern healthcare spending and innovation and are associated with the notion of empowerment.

Thus, not only does empowerment imply notions of equal rights, it also contains meanings associated with health and wellness. In this relationship, empowerment is connected with health as a human right and a lack of health as a form of oppression, an additional dimension that requires placing health equity, access, and self-management at the forefront of

understanding empowerment (Tengland, 2016; Small, Bower, Chew-Graham, Whalley, & Protheroe, 2013; Fisher & Howell, 2010; Holmström & Röing, 2010; Bulsara, 2008; Anderson, 1996). It is in this context that empowerment was adopted by the World Health Organization in 1986 as a fundamental initiative to address global health disparity (WHO, 1986).

However, even with an understanding of the historical dimensions of empowerment, there is still a lack of consensus as to its meaning.

#### *2.3.4 Studying Empowerment*

There is a vast transdisciplinary research literature on empowerment that reflects multiple meanings arising from various historical contexts. The notion of empowerment is utilized in business management and economics (Hardy & Leiba-O'Sullivan, 1998), international development (Grabe, 2012), psychology (Cattaneo & Chapman, 2010), sociology (Christens, 2012), medicine, (Juengst, Flatt & Settersten, 2012), nursing (Laschinger, Wong, & Grau, 2013), social work (Christens & Petersons, 2012), and rehabilitation (Fisher & Howell, 2010; Zimmerman & Warschausky, 1998). Empirically, quantitative, qualitative and mixed methods research studies have all attempted coherent understanding of this concept.

In the domain of health (i.e., medicine, psychology, nursing, social work, and rehabilitation sciences), for example, research on empowerment can be divided into the following types of studies: 1) theoretical papers (Christens, 2012; Schulz, Israel, Zimmerman, & Checkoway, 1995; Rappaport, 1981); 2) evaluation studies (Jurkowski, Lawson, Green Mills, Wilner, & Davison, 2014; Keers et al., 2004; Tsay & Hung, 2004); 3) qualitative exploratory studies (Ernst et al., 2013; Panicker, 2013; Funk, Stajduhar, & Purkis, 2011; Bulsara et al., 2004); 4) psychometric development (Maunsell et al., 2014; Bulsara & Styles, 2013; Van Den

Berg et al., 2013; Small et al., 2013; Bulsara, 2008; Kettunen, Liimatainen, Villberg, & Perko, 2006; Anderson, Funnel, Fitzgerald & Marrero, 2000); 5) correlational descriptive studies (Donahue, Piazza, Griffin, Dykes, & Fitzpatrick, 2008; Via & Salyer, 1999; Artinian, Magnan, Sloan, & Lange, 2002); 6) systematic and scoping reviews (Kuo, Lin, & Tsai, 2014; Morton & Montgomery, 2013; Herbert et al., 2009); and 7) concept analyses (Jerofke, 2013; Ajoulat et al., 2007; Ryles, 1999).

These studies illustrate some of the common characteristics, processes and outcomes of empowerment. For example, qualitative exploratory studies have identified that patients can experience empowerment as an enabling process of re-establishing control over health in particular and life in general, lost to illness or disability (Nygardh, Malm, Wikby, & Ahlstrom, 2011; Bulsara et al., 2004; McWilliam et al., 1997). Evaluation, correlational descriptive and psychometric studies have shown relationships between empowerment with other concepts such as self-efficacy (Moattari, Ebrahimi, Sharifi, & Rouzbeh, 2012; Via & Salyer, 1999), self-esteem and confidence (Corrigan, Faber, Rashid, & Leary, 1999), and resiliency (Johnson, Worell, & Chandler, 2005). Papers that have explored empowerment as a theoretical concept have associated it with theories of health behavioural change. (e.g., Bandura's health belief model) (Tengland, 2016; Bulsara, 2008), and theories of adult learning (e.g., the theory of transformative learning) (Jacobs, 2011; Baumgartner, 2011) that position the phenomenon as a psychosocial process of interpersonal and intrapersonal change.

Notwithstanding some common threads, this body of research contains multiple theoretical renderings of empowerment related to the different theories adduced to make sense of (and perhaps contribute to), the ambiguity of this notion. Critical theory (Fulton, 1997), social/psychological theory (Shearer, 2009), organizational theory (Sarmiento et al., 2004) and

post-structural theory (Foster-Fishman et al., 1998) have offered enough variation of definition to mitigate against a common integrated understanding (Bradbury-Jones et al., 2008; Kuokkanen & Leino-Kilpi, 2001). In order to highlight these various theoretical interpretations, empowerment can be categorically ordered into three different theoretical levels: individual, relational, and systemic, referring respectively to empowerment as an individual process that is also subject to the influence of social interactions (relational) and larger social, political and cultural forces (systemic) (Schulz et al., 1995).

At the individual level, for instance, empowerment is described as a process associated with the ways in which individuals re-establish a sense of control over their beliefs, behaviours and resources in the face of a loss of control over their lives (Christens, 2012; Perkin & Zimmerman, 1995; Rappaport, 1987). Here, empowerment is linked to theories of social psychology such as social learning theory (Bandura), theories of self-efficacy and post-traumatic growth (Bell, 2012; Bulsara, 2008), and self-determination theory (Aujoulat et al., 2007; Conger & Kanungo, 1988), among others. At this individual level, empowerment is seen to emerge from the meaning individuals give to their experience (Christens, 2012; Anderson, 1996; Perkin & Zimmerman, 1995) but as Gibson (1991) notes, attention to the individual level of empowerment risks glossing over the larger social, political and cultural forces that may impact how people construct meaning. For example, Cattaneo & Chapman (2010) provide a well-articulated theoretical model of empowerment at the individual level. Here, empowerment is contingent upon building a sense of self-efficacy, knowledge and competence by pursuing meaningful “power oriented” goals. This theory acknowledges, but makes little reference to, relational and systemic levels of empowerment.

Consideration of the relational level shows that empowerment is understood as a social phenomenon occurring between two or more people, emerging from the dynamics of giving, taking and sharing power (Christens, 2012). Empowerment can also be seen as a process of addressing power imbalances between people; for instance Fishbane (2011) uses a relational form of empowerment that relies on exploring power imbalances to develop a therapeutic intervention designed to address poor dynamics in marital forms of conflict. Quite differently, Wallerstein (1992) draws on theories of community engagement to develop a sense of empowerment, for example a health promotional program that fosters a sense of community and increased participation in decision making. Wallerstein makes references to the systemic level of empowerment by illustrating that physical and social risk factors associated with health can be a source of powerlessness. Reducing them will create a sense of empowerment, but the model provides little indication as to how.

Systemically, empowerment is seen as a broader social construct that includes both individual and relational levels within an expanded framework of social and political factors that include class, race and cultural differences as they impact access to resources. Social ecological theory (Jurkowski et al., 2014) and theories of social action (Chen, Mullins, Novak, & Thomas, 2016; Wallerstein, 2002) inform this level of empowerment, where the concept is more complex and multi-layered, involving as it does an intertwined exploration of the other levels as they relate to access. For example, Bravo et al. (2015) provides a theory of patient empowerment that incorporates a systemic approach by including healthcare access as an element of the empowerment process. In this model, each level of empowerment is seen as a contributing factor to patient empowerment. The individual patient level reinforces that the patient has rights and needs to take responsibility over their health while at the relational level, healthcare

professionals need to create an environment that supports patient empowerment by developing a collaborative relationship of shared decision making that respects the patient's right to be autonomous. However, Bravo also illustrates that the ability to create this collaborative environment is reliant on a responsive healthcare system that provides access to care such as chronic disease self-management programming, personalized care planning and patient education. Thus, the systemic level plays a critical role in the empowerment process of the individual by contributing to different indicators of patient empowerment that enhances patient and clinical outcomes such as the person's ability to adapt to a chronic illness, quality of life, independence and health status.

While incorporating a number of dimensions of empowerment, Bravo's model is limited in that it emphasizes a series of assumptions that empowerment involves processes associated with optimizing healthcare utilization. This optimization occurs through the provision of support and skills to ensure that individuals are autonomous and self-determined. These assumptions are embedded in a specific understanding of empowerment based on theories of behavioural change that focus on changing perceptions around control and autonomy to help the person become more active and engaged in their healthcare. This is a very limited understanding of empowerment that emphasizes decision-making without considering the complexity of individual experiences. Powers' (2003) critical stance further informs my critique: "Health professionals believe they are performing a service by empowering individuals to make correct choices in their lives. Patients are considered empowered, however, if and only if they make the correct choices as defined by the health care provider" (p. 227).

In addition, there are potentially many variations of the meaning of autonomy and what it means to be ill. Bravo's model is problematic because it reflects the cultural assimilation of one

specific view of illness. This type of assimilation may be perceived as a form of oppression. Thus, although Bravo's model does incorporate attributes that reinforce respecting the viewpoints of the patient, it seems to reinforce only one way of responding to illness while neglecting different cultural views of what it means to be sick.

Nonetheless, while empowerment is differently interpreted across the individual, relational and systemic levels, there appears to be an overabundance of studies in the healthcare literature that explore individual and relational forms of empowerment. For instance, there is considerable research focused on developing and testing interventions that promote empowerment through self-management at the individual level (e.g., Maunsell et al., 2014; Bulsara & Styles, 2013; Van Den Berg et al., 2013; Small et al., 2013). This research has a strong focus on the development of self-efficacy in the individual. Equally, there is ample research within the relational level framework that explores the emergence of empowerment from strengthened relationships and collaborative potential between patients and clinicians (e.g., Ernst et al., 2013; Panicker, 2013; Funk et al., 2011; Donahue et al., 2008; Kettunen et al., 2006). Within this literature, fewer studies investigate the systemic level of empowerment. For example, Aujoulat et al. (2007) notes in their concept analysis that the majority of their articles included in their review were either evaluation studies aimed at measuring self-management behaviours or clinician patient interactions.

This imbalance in the research on empowerment indicates that fewer studies have investigated whether enhanced control and autonomy at the individual and relational levels can address barriers in access to healthcare – a missing piece that could well explain why so many self-management interventions have found inconsistent relationships between enhanced patient control and autonomy and improved health outcomes (Kuo et al., 2014; Morton & Montgomery,

2013; Herbert et al., 2009). Self-management and access to resources seems to be integral characteristics of the empowerment process, yet it appears studies exploring these connections have found poor connections (Panagioti et al., 2014; Weaver, Lemonde, Payman, & Goodman, 2014; Jaglal et al., 2014). For example, Weaver et al. (2014) illustrates that a person's ability to self-manage diabetes was impacted by the socio economic status of the individual and their ability to afford medical devices that enhance the management of this illness. Thus, even though there exists an extensive body of research literature on empowerment, its depth and scope is somewhat limited. Implications of such limitations can be concerning given the connections between empowerment, self-management and addressing issues associated with health equity.

### *2.3.5 Challenges of Exploring Empowerment*

There is no denying that research on empowerment is vast and uses a number of theoretical approaches and a wide variety of methods. But even with this variation, this literature suffers from several limitations. First and foremost, there is no agreed upon definition of empowerment. Because of the range of meanings associated with empowerment, its embedded processes associated with addressing concerns associated with control and autonomy vary considerably. Critical theory, organizational theory, post-structural theory and theories associated with social/community psychology provide different conceptual understandings that mitigates against an integrating understanding of what is involved in its processes. Without an integrated understanding, models that outline the processes of empowerment such as those provided by Bravo et al., (2015) that focus on one conceptual understanding may be oppressive to the individual rather than creating a sense of autonomy. Thus, without an integrated understanding, empowerment will continue to be a concept that will be difficult to apply. For example, it will

continue to be difficult to explore and create any type of health intervention addressing concerns related to this phenomenon, such as control and access to health resources without a clearer understanding of how this phenomenon applies to the individual's illness experience.

Second, existing studies heavily favour deductive forms of inquiry. Aujoulat et al. (2007) note in their concept analysis that half of their selected research articles (15/27) were evaluation studies using randomised control trials, quasi-experimental studies and longitudinal pre-test/post-test designs aimed at measuring the impact of empowerment-based interventions on individuals. These types of deductive forms of inquiry provide a specific but limited understanding of empowerment, an observation shared by others (Bravo et al., 2015; Jerofke, 2013).

Finally, as I have discussed, empowerment is considered a complex social phenomenon that is largely interpretive, based on the perceptions, experiences and meanings attributed by those who are studied (Kieffer, 1984; Gibson, 1991), the very perspective that is missing from the literature. Most studies define empowerment at the outset to clarify what characteristics of the experience are being explored. However, defining the concept at the beginning of the study can influence sampling procedures by only interviewing participants who can speak about those specific characteristics rather than exploring variations in its experience. The result is that a phenomenon rich and diverse in meaning is severely reduced in scope of interpretation. For example, of the small number of qualitative inquiries to explore empowerment as it relates to cancer, strikingly few researchers ask their participants to define what it means to them (Stang & Mittelmark, 2008; Bulsara et al., 2004; Mok, 2001). In a phenomenological inquiry, for instance, the sample was based on a preconceived definition of empowerment as the ability to control and self-manage an illness (Bulsara et al, 2004). As a result, those who already felt a strong sense of control over their cancer were sampled. Bulsara et al's findings, based on qualitative interviews

with seven hematology cancer patients (5 men and 2 women with ages ranging from 39 to 63 years), show that empowerment emerged when participants found a balance between fighting for control and accepting periods of limited or no control, a finding that seems to have skewed understanding.

To recap, given the limitations discussed above, three overarching challenges emerge for research on empowerment. First, without a comprehensive understanding of the notion of empowerment consolidating its various interpretations, empowerment will continue to evade researchers. One way to address this challenge is to ask participants to define empowerment for themselves, allowing researchers to find commonalities within this variation, which would allow for construction of an integrated understanding of how this emergent experience is understood by them.

Second and closely related, researchers continue to debate exactly what empowerment might be. Many scholars have noted that it is far easier to define empowerment based on its anticipated outcomes rather than its very nature (Aujoulat et al., 2007). As a consequence, empowerment gets bundled with other related concepts such as patient activation, engagement, participation, and enhanced self-efficacy without exploring the specificity. Once again, to address this concern, participants could be asked what empowerment means to them so that researchers can distinguish empowerment from similar concepts.

Finally, there have been a number of attempts to quantify empowerment (Maunsell et al., 2014; Bulsara & Styles, 2013; Van Den Berg et al., 2013). Since it is an important health related concept, it seems both practical and necessary to explore the phenomenon using a population based approach. In response, several scales have been developed and validated. Yet, when taking a closer look at such measurements, it becomes apparent that they are not measuring

empowerment per se, but rather quantifying relatable concepts like self-efficacy, for example (Maunsell et al., 2014), or aspects that might be linked without primary knowledge of what empowerment is (Bulsara & Styles, 2013). The debate has therefore ensued as to whether empowerment is a quantifiable concept. While some have argued it is, others assert the difficulties of measuring a phenomenon that is complex and process-based and therefore highly diverse (Zimmerman, 1990). As with the other challenges, it seems unlikely that this conundrum can be addressed without first exploring empowerment from the individual's perspective. Until such time, empowerment will remain ambiguous, and attempts to quantify it may be considered problematic.

In summary, it is clear that the meaning of empowerment from the perspective of patients has not been sufficiently explored. With a lack of emphasis on its theoretical understanding and the processes embedded in its experience, it is difficult apply empowerment in any type of intervention design or outcome measure that addresses concerns associated with health equity and access related to quality of life in cancer care. In addition, some authors who have challenged the popular notions of empowerment that dominate the cancer survivorship discourse have observed that the emerging empowerment narrative may be inadvertently causing harm to cancer survivors. For example, Sinding et al. (2012) argue that the close associations drawn between empowerment, self-management and patient activation result in a conceptually flawed understanding that rests on the assumption that people want to be in control and involved in their healthcare. Sinding also suggests that the push for patient involvement, which may appear to be about empowerment, is actually reflective of the need to contain healthcare costs by shifting responsibility for quality healthcare away from the cancer care institution to a more collaborative framework that radiates out to the individual. One question that emerges in this context is

whether the shift in a sense of responsibility from healthcare system to individual is ethical, considering the psychological, physical and social impacts entailed by a diagnosis of cancer and its consequent treatments. Could such increased responsibility be perceived as empowering? If so, are there nuances to be found in balancing individual involvement and institutional responsibility? These questions remain unexplored. In the field of cancer rehabilitation where autonomy, control and participation are foundational concepts, it is clear that a better understanding of empowerment is imperative in order to tackle the existing gaps experienced by those who are struggling in the wake of a diagnosis and treatment of cancer.

## ***2.4 Cancer Rehabilitation***

### *2.4.1 Introduction*

Cancer rehabilitation is a rapidly emerging and evolving area devoted to addressing functional concerns arising from a diagnosis of cancer and the side effects of its treatments. Together with supportive and palliative care, cancer rehabilitation is a sub-specialty that shapes the field of cancer survivorship care, which arose in the mid-1980s as awareness grew concerning the long-term consequences associated with greater numbers of people surviving cancer. However, in comparison with supportive and palliative care, rehabilitation remains the least developed of these subspecialties (Alfano et al., 2012; Cheville et al., 2011; Cheville & Tchou, 2007; DeLisa, 2001). Scholars have noted several gaps in knowledge creation and dissemination associated with rehabilitation in comparison to its close counterparts (Kristiansen, Adamsen, & Hendriksen, 2013). As a result, evidence concerning cancer rehabilitation is limited and narrowly focused. Consequently, many cancer survivors are left on their own to live with and adapt to any functional limitation emerging from their diagnosis and treatments, with

clinicians inadequately resourced to help them. To begin to address these gaps, the full scope of the field needs to be understood.

#### *2.4.2 Rehabilitation*

Rehabilitation is an inter-professional area of healthcare aimed at addressing functional limitations associated with any form of disability, disease and treatment side effect (Egan et al., 2013). The treating rehabilitation team may include psychiatrists; occupational, physical, and recreational therapists; speech/language pathologists; social workers; psychologists; vocational counselors; and not least of all, patients and their significant others (DeLisa, 2001). The aims are to restore and optimize the level of functioning of the individual to allow full participation in daily activities and life roles that may have been reduced because of a health related condition (Stucki, Cieza, & Ewert, 2002). This includes enabling the individual to regain lost elements of their life such as physical functioning or personal and social identity, and to adapt to a less accessible environment, which may require learning new skills (Davis & Madden, 2006).

Accordingly, rehabilitation defines itself with respect to concepts of function, disability and health (Stucki et al., 2002). Many frameworks ranging from simple linear models (Hughes & Patterson, 1997) to highly abstract models (Iwama, Thomson, & MacDonald, 2009) have been generated to position these concepts in relation to an illness or physical condition. Those of the simple variety follow a biomedical approach and understand a lack of function as a direct response from a person's physical or mental condition (Mitra, 2006). Moving towards more abstract understandings, social and geographical characteristics are included to illustrate that participation restrictions may also be due to other factors such as a social environment that discriminates against certain conditions (Hughes & Patterson, 1997). The addition of

environmental and social factors politicizes the field of rehabilitation by introducing social determinants, adding other dimensions to the traditional regard of disability as emergent from a physical condition alone.

#### *2.4.3 Situating Rehabilitation in Cancer Survivorship*

Cancer rehabilitation has long been a part of the management of this illness, but with increased survivorship, these efforts have evolved from simple supportive and palliative care to complex interventions (Gilchrist et al., 2009). Rehabilitation is a process that can begin the moment an individual is diagnosed (Howell et al., 2009). Threats to participation can occur through every stage of illness. Most notably, cancer treatments are toxic and harmful to the physical body and threaten a person's ability to be autonomous and engage in their life in meaningful ways. Therefore, strong emphasis is placed on creating less invasive cancer treatments and managing the consequences of their side-effects, thereby reducing this particular threat (Fu et al., 2015; Silver et al., 2015). Furthermore, there is a new movement in cancer rehabilitation, called prehabilitation, that attempts to strengthen the physical body before treatment begins in order to counteract these harmful effects (Silver & Baima, 2013).

The stress associated with a diagnosis can also be debilitating. Distress is a common concern across the cancer trajectory, beginning at diagnosis and extending to the post-treatment stages (Howell & Olsen, 2011). The word cancer (often referred to as "the big C"), is perceived as a threat to one's life and therefore can constitute a chaotic event. Studies have reported that some people have difficulty participating and advocating for themselves throughout critical transition points when survivors may be most vulnerable to unmet psychosocial needs and emotional distress (Richardson et al., 2015; Howell & Olsen, 2011; IOM, 2008).

Over the last decade, there has been a strong emphasis on screening for distress, an international initiative driven by Canadian researchers that seeks to uncover psychosocial concerns at every cancer associated appointment. Screening has become a provincial mandate in all Ontario tertiary cancer centers and now includes assessing functional and participatory indicators (e.g., the Improving Patient Experience and Health Outcomes Collaborative from Cancer Care Ontario). Notwithstanding these innovations, cancer rehabilitation remains an underdeveloped subspecialty of cancer survivorship care (Loh & Musa, 2015; Silver et al., 2015; Egan et al., 2013; Cheville & Tchou, 2007).

There is no clear reason as to why this should be the case, although many scholars have noted a series of possible explanations related to the development of the field (Alfano et al., 2012; Cheville et al., 2011; Franklin, 2007). The first conceptual framework for cancer rehabilitation was created in 1969 by Herbert Dietz (Franklin, 2007). Dietz classified four areas of cancer rehabilitation: preventative, restorative; supportive, and palliative, with each one focused specifically on participation and functional autonomy. However, over the next four decades, function and participation as primary outcomes were overshadowed by a stronger emphasis on reducing the length of hospital inpatient care. This period saw the rise in cancer survivorship discourse that placed a stronger need for self-management and outcomes specific to reducing symptom burden, thereby diminishing the opportunity to explore the full scope of cancer rehabilitation (Alfano et al., 2012). Alfano et al. (2012) note that consequently, existing rehabilitation services tended toward a one-dimensional focus on addressing physical symptoms rather than the comprehensive assessment and treatment of needs related to function and participation in daily living.

Indeed, the current state of the evidence in cancer rehabilitation reflects this one dimensional view. In the most recent systematic review to assess the state of the literature, Egan et al. (2013) show that rehabilitation interventions are limited in depth and scope by a heavy focus on reducing symptom burden; very few studies identified address the issues related to participation in daily living. For instance, while good evidence exists for the use of physical rehabilitation in reducing fatigue after treatment for most cancers, and improving upper extremity functioning following treatment for breast cancer, there is only preliminary evidence that other interventions work, and very few outside of return to work interventions focused on participation as a primary outcome (Egan et al., 2013). Thus other gaps remain with respect to other functional and mental health concerns such as depression/anxiety, mobility, pain and sexuality. These assertions are supported by other systematic reviews (Hunter et al., 2017a; Hunter et al., 2017b; Salakari et al., 2015).

Participation is critical to rehabilitation because difficulties engaging in one's life illustrate an emerging functional limitation. Yet, according to Egan et al (2013), participation problems tend to be addressed as concerns relevant to health-related quality of life (HRQL). However, HRQL tools are limited in the scope of participation issues they address (Van Der Mei, Dijkers, & Heerkens, 2011). These limitations include addressing behaviours associated with self-management, which by definition is a participatory behaviour related to fundamental goal in rehabilitation directed at self-care. Yet, in the most recent systematic review to explore self-management, Howell et., al (2017) illustrate that of the 42 randomized control trials examining self-management interventions for cancer patients, the authors highlight that a core set of participatory principles for building a successful self-management program could not be identified. These findings are corroborated by an earlier systematic review (McCorkle et al.,

2011). Therefore, what seems to be missing is a comprehensive understanding of the participatory behaviours of cancer survivors as they encounter challenges associated with participation. Challenges can be numerous, but without an orientation towards participation, it is unlikely that any type of evidence based intervention will move beyond a one dimensional understanding of cancer rehabilitation.

Without expanding upon cancer rehabilitation, there remains many knowledge gaps that perpetuate the problems inherent in the field. First, identifying participation restrictions can be difficult since most patients with cancer do not experience abrupt changes in functional status until the last few months of life. Studies exploring functional decline of cancer survivors suggests that cancer-related disablement is an insidious process that gradually erodes function over time, and gradual changes often go unnoticed until later stages of the illness (Petrick et al., 2014; Cheville et al., 2011; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). Furthermore, function is a social concept. What may appear to be a functional limitation in one environment, may not be in another. Therefore, survivors and clinicians are not always aware of a degradation to participation and thus find it difficult to assess and discuss.

Second, cancer care is predominantly focused on treating the physical condition with less attention devoted to function as a primary outcome. As a consequence, there is a general lack of training in identifying functional issues. There is an inherent assumption embedded in cancer care that treating the physical condition or managing and controlling a symptom will counteract any risk to participation in daily living. Yet, this is not always the case. How symptoms are managed must be dictated by what is meaningful to the individual. In other words, survivors will adapt or live with any condition without addressing it fully if they are able to participate in their life in meaningful ways. Therefore, there may be times when adaptation should take precedence

over symptom control, notwithstanding the tendency in cancer rehabilitation to focus on symptom management rather than participation in daily living.

#### *2.4.4 Models of Rehabilitation in Cancer Survivorship*

As noted, rehabilitation is a process of addressing any functional limitation that emerges from an illness or health condition that imposes on one's ability to participate in daily living. Addressing these limitations in an effective way requires a combination of physical conditioning with reinforcing skills that may help the person adapt to changes resulting from illness and their interactions with the environment. Yet, of the rehabilitation models designed to address participation related issues associated with cancer, none appear to fully integrate these elements.

Only two models were identified that explore rehabilitation for cancer survivors: 1) The Prospective Surveillance Model (PSM) (Cheville et al., 2017; Stout et al., 2012; Gerber, Stout, Schmitz, & Stricker, 2012); and 2) The Stained Glass Cancer Rehabilitation Framework (Pearson & Twigg, 2013). These models are very different, from conceptualization through utilization and validation.

The perspective surveillance model was developed specifically to address functional concerns related to breast cancer related surgery. Rehabilitation begins at diagnosis with a multidimensional, comprehensive assessment, usually conducted preoperatively, followed by serial, scheduled follow-up visits with a specialized provider. Evaluation at the time of diagnosis establishes patients' baseline functioning and identifies individuals with pre-existing conditions who are potentially predisposed to developing impairments. The model focuses on identifying symptoms and functional issues amenable to rehabilitation and then linking these to interventions.

The strength of the Prospective Surveillance Model lies in its attention to ongoing follow-up with visits at established intervals to a specialized provider. The intent of the follow-up is to monitor for any impairment of concern related to participation. This is a highly relevant feature for rehabilitation since cancer-related disablement can be such a gradual process that it is difficult to notice. However, the model is limited in a number of areas. For one thing, it was designed to address functional concerns related to breast cancer surgery, a specific focus that makes it challenging to adapt for a broader cancer population. Secondly, the model may not be feasible since it relies heavily on the kind of infrastructure that provides for constant monitoring by specialists, which would also depend on survivors being willing to be constantly assessed for change. Thus far, the model has only been tested in one site, Walter Reed National Military Medical Center in Bethesda, Maryland, with 196 breast cancer survivors (Cheville et al., 2017). Of most concern other than an exclusive focus on breast cancer, are the survivors' experiences adapting to a specific participatory limitation. There is a breadth of literature on disability studies related to participation restrictions that explores how people naturally adapt to an illness (Psarra & Kleftras, 2013; Livneh & Parker, 2005; Charmaz, 1995). For example, theories of transformative learning (Dubouloz et al., 2010) have explored adaptive behaviours in other populations. This focus has yet to be explored in a cancer context, outside of theories associated with post-traumatic growth (Occhipinti, Chambers, Lepore, Aitken, & Dunn, 2015; Shand, Cowlshaw, Brooker, Burney, & Ricciardelli, 2015; Connerty & Knott, 2013). The same issues, I would argue, plague the Stained Glass Cancer Rehabilitation Framework.

Unlike the perspective surveillance model (PSM), the Stained Glass Cancer Rehabilitation Framework has not been tested in any cancer population for its efficacy or feasibility. In fact, no critique of the model can be found. Developed for a generalized cancer

population, the framework arose from an investigation into survivor needs for cancer rehabilitation (Pearson & Twigg, 2013). Key elements that emerged were: identification of needs (screening), diversity of needs, stratification of rehabilitation, and different settings for delivering rehabilitation. But the model also fails to consider participatory behaviours that reveal processes adopted when patients encounter any type of restriction. Understanding such participatory behaviours is arguably a valuable missing component when trying to understand and guide survivors through a rehabilitation process.

It is this missing piece that provides the driver for this doctoral study. By definition, empowerment is about taking or re-establishing oneself in situations where control is lost and is very much in line with what occurs when people experience a participation restriction or a loss in function. Exploring empowerment in a cancer rehabilitation context opens a gateway to study the participatory behaviours of cancer survivors as they encounter challenges; it seeks to address the gap in knowledge demonstrated in this literature review concerning how survivors participate in their life even while broaching restrictions to daily living.

#### *2.4.5 Situating Empowerment in Cancer Rehabilitation*

The concept of empowerment and the process of rehabilitation are inherently linked (French & Swain, 2008). Rehabilitation is generally referred to as an enabling process for restoring and optimizing the level of functioning of the individual to allow full participation in daily activities and life roles that may have been reduced because of a health related condition (Stucki et al., 2002). Some ways that this occurs is through patient education, health promotion, and patient engagement that support individuals to feel more in control and competent to make decisions, in other words to re-engage in their lives at a level that brings them a degree of health,

satisfaction, and meaning (Egan et al., 2013). Therefore the concepts of control and autonomy are implied in the definition of rehabilitation, making empowerment a fundamental concept in the field (Zimmerman & Warschausky, 1998; Davis & Madden, 2006; Houser, Hampton, & Carriker, 2000).

Although empowerment is not directly referred to in any cancer rehabilitation model, the concept falls most readily within the participation domain, considering that the most common definitions of rehabilitation are associated with functional autonomy, increased control and participatory behaviours related to the self-care of the individual (Shearer, 2009; Dubouloz, Vallerand, Laporte, Ashe, & Hall, 2008; Wang, Dong, Gan, Bin, & Wang, 2007; Dubouloz, Laporte, Hall, Ashe, & Smith, 2004; Zimmerman & Warschausky, 1998; Perkins & Zimmerman, 1995). Self-care (often used interchangeably with self-management) refers to the individual's capacity to manage the symptoms and consequences of living with a chronic condition while being able to engage in maintaining and enhancing their own health and well-being (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001; Bodenheimer, Lorig, Holman, & Grumbach, 2002; Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; McCorkle et al., 2011). The ability to effectively care for oneself includes having access to information, resources and support to assist with control and autonomy over an individual's life (Wang et al., 2007). Connected with the domain of participation, the process of empowerment should emerge as individuals gain sufficient control to allow participation in what they would consider as meaningful activity, regardless of their health condition. This process would trace the complex interactions between the nature of the health condition, the personal factors of the individual and the characteristics of the person's immediate social environment. Yet, this experience of empowerment remains unfounded since it has yet to be explored from the perspective of post-treatment cancer

survivors. It was the intentions of this doctoral study to explore empowerment from this perspective.

### ***2.5 Current Study***

Given the paucity of research concerning the definitions and uses of empowerment in cancer survivorship and rehabilitation, the purpose of the current study was to explore empowerment from the perspective of cancer survivors using the following primary and secondary research questions:

#### *Primary research question*

- In what ways do cancer survivors define, describe and/or experience the processes of empowerment?

#### *Secondary research questions:*

- How do cancer survivors describe the emergence of empowerment within various contexts and relationship related to their illness? (i.e., how does empowerment emerge in relation to establishing control over aspects of their illness and/or life as they interact with their care providers, family members and other parts of their social environment?)
- What are the connections and relationships between processes of empowerment, patient engagement and education, care planning, decision-making, and self-management from the perspective of survivors?

By exploring these questions, I am able to re-define empowerment based on the perspectives of cancer survivors and to explore the processes that underlie its experience. In doing so, I outlined the characteristics of the experience in relation to commonly held assumptions and beliefs about the phenomenon and how it can be applied in cancer survivorship and rehabilitation regarding how individuals cope with the multiple ways cancer can cause impairments and disabilities.

## ***2.6 Summary***

Significant knowledge gaps exist in the delivery of cancer rehabilitation and the ways in which the concept of empowerment is applied. The idea of empowering individuals by giving them more control over their cancer care is a valuable notion considering the lack of infrastructure to handle the increasing number of people surviving the illness. In addition, the notion of empowerment plays an important role in cancer rehabilitation by describing a process to re-establish control to regain some semblance of autonomy that may have been lost as a result of a cancer diagnosis and treatment side-effects. Yet, empowerment remains an elusive and complex phenomenon. This contributes to a lack of awareness as to how survivors re-establish control when they encounter challenges associated their diagnosis and treatments. The purpose of this doctoral study was to establish a clearer understanding of this phenomenon by exploring its underlying social processes from the perspectives of survivors.

## **Chapter 3**

### **Study Design and Methodology**

#### ***3.1 Introduction***

The present study endeavors to broaden our understanding of the experiences of post-treatment cancer survivors by exploring the social phenomenon of empowerment. Since the post-treatment survivorship and rehabilitation phase of the illness is characterized by a decrease in professional and social support, survivors are increasingly required to take a more active and participatory role in the long-term management of their care. As such, there has been an increased emphasis on developing patient-centred self-management approaches that “empower” survivors to be more actively involved and in control and capable of addressing their post-treatment physical, psychosocial and rehabilitative needs. The purpose of this research was to explore empowerment from the perspective of post-treatment cancer survivors. The goal was to create a theory that could incorporate a variety of interpretations as well as shared meanings of empowerment, bringing clarity to a pivotal experience in the post treatment management and rehabilitation of cancer survivors.

To meet the objectives of this study, I engaged in semi-structured interviews with 22 post-treatment head and neck (head/neck) and breast cancer survivors to explore their meanings, experiences and processes of empowerment as related to beliefs and perceptions about cancer; and to reveal the social interactions and behaviours related to the management of physical and psychosocial consequences of diagnosis and treatments. Using a qualitative research design with a social constructivist (interpretive) theoretical lens and the grounded theory method informed by the work of Kathy Charmaz (Charmaz, 2014), I compared and contrasted themes that emerged

from the data from participant narratives with my own emerging knowledge of the concept. This method of comparison allowed me to construct a substantive theory of the empowerment process grounded in participants' experiences and perspectives. In this chapter, I outline the procedures and processes that I followed, beginning with an overview of my research design, followed by the principles of social constructivism, and concluding with an outline of my data collection and analysis procedures.

### ***3.2 Qualitative Research Design***

A qualitative research design is a line of inquiry that studies social phenomena in their natural settings. It consists of a set of interpretive and material practices that “make the world visible” while attempting to make sense of the meanings people create (Denzin and Lincoln, 2005, p3). Qualitative research involves studying and collecting a variety of materials (e.g., via texts, transcripts, journals, and observations) that describe experiences and meanings in individuals' lives. This form of research is different from other traditions of inquiry such as quantitative research that studies social phenomenon in controlled environments that emphasize objectivity and generality. The philosophies of quantitative research are based on the assumptions that human experience is something that can be measured, controlled, and studied objectively to test hypotheses and make causal inferences and generalizations that predict human behaviour. However, the range of human experience with cultural, political and social meanings cannot be accounted for when studying social phenomena using quantitative approaches (Charmaz, 2014). Methodologies that take this type of objective approach are less equipped to identify the underlying meanings because they are unable to account for the complex variations of human experience (Foster-Fishman et al., 1998).

In comparison, qualitative research attempts to secure an in-depth understanding of human experience by seeking to capture the core assumptions individuals attribute to their experience. One of the key strengths of qualitative research resides in its capacity to provide complex textual descriptions of individuals' experiences through a variety of data collection techniques such as interviews and focus groups (Cresswell, 2013). It is this style of empirical study that is missing from the exploration of empowerment. In the literature, empowerment is typically explored using quantitative approaches that are not equipped to capture the nuances of a phenomenon that is complex, largely interpretive and socially constructed (Aujoulat et al., 2007).

### ***3.3 Social Constructivism***

In qualitative research, there are a number of theoretical frameworks (philosophical world views) that present differing ontological and epistemological ways of understanding the world. Some examples of such variant views are post-positivism, social constructivism, transformative, and pragmatic theoretical frameworks (Creswell, 2014). Each system provides a different way to look at social phenomenon that will necessarily shape the research design and methods used to collect and analyze data (Creswell, 2014). To explore empowerment, I chose social constructivism as the theoretical framework to guide this research. Social constructivism is defined as a framework that views reality as something that is shaped by the social interactions, subjective interpretations, and shared meanings between people, treating reality as the co-creation of knowledge between individuals understood to emerge from unique historical and social perspectives that inform multiple ways of understanding the world (Charmaz, 2014). As such, social constructivism emphasizes the importance of capturing individuals' unique realities and how they understand their social world (Foster-Fishman et al., 1998).

The emphasis of constructivism on multiple realities makes it a good framework for exploring empowerment. Since the essence of an empowering experience resides in individual interpretations and interactions, the choice of a social constructivist lens for this study provided a way to explore and illuminate the multiple ways that empowerment is understood in the context of cancer survivorship and rehabilitation. This type of exploration has been rare since empowerment is typically explored using theories such as social theory, critical theory, and organizational theory that cannot account for multiple renderings.

As a theoretical framework, Creswell (2014) defines four characteristics of social constructivism that allow researchers to explore various ways people define and experience phenomenon. These characteristics are:

- 1) *Human beings construct meanings as they engage with the world.*
- 2) *Meaning is socially constructed, arising from interactions between people and their social and historical context. This includes the interactions between the researcher and their study participants that together generate meanings of the social phenomenon being studied.*
- 3) *Social constructivism relies as much as possible on the participants' views of the situation being studied.*
- 4) *Researchers who use social constructivism seek to understand the context and setting of the participants by collecting data in the field*

(Cresswell, 2014, p. 8)

It is important to note that within social constructivism, researchers are not seen as objective observers, but rather as active participants in the co-creation of meaning (Creswell, 2014; Charmaz, 2014; Mills et al., 2006). This is a unique feature when compared to theoretical traditions that treat researchers as objective observers outside the world of their participants. Research methods adopting a social constructivist lens consider the perspectives of researchers, which are used to illuminate the meanings of participants in a process of confirmation and disconfirmation of their own insights as they collect and analyze their data. It is a process that ensures researchers can capture the meanings ascribed by participants to their experience and

insofar as possible refrain from superimposing their own interpretive biases. With this intention, qualitative methods that adopt social constructivism use specific techniques such as reflexive journaling and memo writing to illuminate and account for researchers' interpretations and worldviews in the co-creation of meaning with their participants.

There are a number of qualitative research methods that adopt social constructivism as a theoretical lens. These include phenomenology, narrative inquiry, interpretive description and grounded theory. Since the purpose of this research was to explore the different meanings of empowerment to generate a theory that could illuminate the processes of the experience, grounded theory was the optimal choice over other qualitative research methods.

### ***3.4 Grounded Theory***

Grounded theory is an abductive<sup>1</sup> form of qualitative research used to construct theories about human behaviour (Ellis & Clark, 2015; Charmaz, 2014; Dune, 2011). These theories are used to establish quantitative, mixed methods and qualitative research to understand how people experience social phenomenon that current theory is unable to fully explain (Glaser & Strauss, 1967). Grounded theory is rooted in the Chicago School of sociology, symbolic interactionism and pragmatic philosophy, which position human behaviour as a force driven by the exchange of meanings and symbols that people give to objects and experiences (Starks & Trinidad, 2007; Charmaz 2006; Annels, 1996; Glaser & Strauss, 1967). This foundation forms the basis for grounded theory development.

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<sup>1</sup> Abduction is a type of reasoning that includes inductive and deductive processes to explore social phenomenon. Abduction begins with inductive reasoning to develop theoretical explanations about observable data. Then, through deductive reasoning, these theoretical explanations are confirmed or disconfirmed by re-entering the field and constantly comparing new data with old data until the most plausible theoretical interpretation emerges (Charmaz, 2014, p. 200).

Grounded theory was introduced by Barney Glaser and Anselm Strauss in 1967 to generate theory about human behaviour. Integrating the systematic approach of quantitative methods with the experiential depths of qualitative research, Glaser and Strauss produced what they called grounded theory (Walker & Myrick, 2006). The research methods for grounded theory are iterative and emergent, meaning that data collection and analysis occur at the same time, shaped by the research questions and the insights of the researcher immersed in data collection and analysis. The research process relies on purposeful and theoretical sampling and semi-structured interviews that follow a process called constant comparative analysis, which involves comparing, contrasting and coding all relationships within the data to develop themes and categories that most closely describe the data. Purposeful sampling is a strategy used to find participants who meet specific inclusion criteria, normally defined as participants who can speak about the social phenomenon under study and who are comfortable sharing their experiences during an interview (Coyne, 1997). Theoretical sampling is a strategy used later in the theory building process that relies on previously collected data to determine the best type of data to elaborate a deeper analytical understanding of the phenomenon (Draucker, Martsof, Ross, & Rusk, 2007; Coyne, 1997; Corbin & Strauss, 1991). Constant comparative analysis together with purposeful and theoretical sampling constitutes the core of qualitative analysis for grounded theory, requiring researchers to collect, analyze and code their data simultaneously, using it to drive the investigation forward. This process continues until nothing novel is being learned about each emerging theme, a condition known as theoretical saturation (Mitchell, 2014; Charmaz, 2014; Boeije, 2002).

As coding occurs, researchers piece together the most salient themes and categories, outlining those properties and relationships that will eventually constitute their theory. To ensure

researchers capture the perspectives of their participants, researchers engage in memo writing and reflexive journaling to help them illuminate their thoughts. These procedures ensure that participants' views will be fully captured while the researcher's thoughts and biases are not superimposed (Gentles, Jack, Nicholas, & McKibbin, 2014). Consequently, grounded theory is a rigorous and reliable research method that goes beyond mere description of a process, offering an explanatory theory that brings taken-for-granted meanings to the surface.

Since the introduction of this research method, grounded theory has evolved into two distinct types: the traditional or classical grounded theory (Glaser & Strauss, 1967) and constructivist grounded theory (Charmaz, 2014). While these two forms of grounded theory do not differ significantly in their research methods, they do differ epistemologically. For instance, in constructivist grounded theory, knowledge is understood as a subjective co-construction between researchers and their participants. In contrast, traditional grounded theory approaches meaning from a post-positivist lens and treats knowledge as an objective creation outside of the world of researchers (Charmaz, 2014; Walker & Myrick, 2006; Glaser & Strauss, 1967). These different interpretations entail a shift in the roles and relationships between researchers and their participants, positioning them as either objective observers (post-positivist) or subjective participants and co-creators in meaning (social constructivism). Understandably these variations change the way that researchers interact with their data and its codification (Charmaz, 2014). For example, constructivist grounded theory uses a three-step iterative and flexible process of initial, focused and theoretical coding, while traditional grounded theory employs a more systematic three-level approach of open, selective and axial coding. Although they are comparable procedures, the difference comes in the coding process; for instance in traditional grounded theory, the researcher moves the coding from one level to the next, while in the constructivist

grounded theory, the coding process moves iteratively and flexibly between coding levels to pinpoint the most salient themes and categories.

My choice of constructivist grounded theory to explore empowerment was based on its theoretical alignment with the social constructivist theoretical lens that recognizes the co-construction of knowledge as a dynamic occurrence between individuals and their perceptions of their social environment, an appropriate type of grounded theory for understanding the multiple meanings ascribed to empowerment, something that other lenses are not capable of capturing. Moreover, my choice of the constructivist theoretical lens in grounded theory was based on Denzin and Lincoln's premise that the researchers' own beliefs and feelings about the world should be considered when choosing how to conduct research (Denzin & Lincoln, 2005). As a researcher, I believe I am not a passive objective observer, but rather an active participant in the creation of meaning. Based on my epistemological and ontological leanings, I subscribe to the understanding that interactions with my participants will necessarily influence not only what knowledge is shared but also how it is constructed. Since these views are consistent with a social constructivist theoretical lens, choosing constructivist grounded theory allowed me to become aware of and acknowledge my own worldviews and prior knowledge; this in turn allowed me to capture the experiences of my participants. Thus by using the constructivist grounded theory method, I could explore and address gaps in the literature concerning the social phenomenon of empowerment, an experience that is central to the post-treatment management and rehabilitation of cancer survivors.

Guided by my research questions, I was able to identify the process in relation to commonly held assumptions of what we believe empowerment to be and how it occurs. The outcome of this study is a theoretical framework to explore the participatory and self-

management behaviours of cancers survivors that can be used to design and test cancer rehabilitation interventions, an area of cancer survivorship that lacks empirical knowledge and evidence informed practice. Taking these two outcomes together, we now have a more comprehensive understanding of a phenomenon that speaks to how survivors manage the consequences of their illness and treatments.

### ***3.5 Methods***

To achieve the goals of this research, I purposefully sampled 22 adult cancer survivors of the head/neck and breast and conducted one semi-structured interview with each participant to explore their thoughts and perceptions about empowerment. Using analysis techniques of constant comparison, coding and memo writing consistent with the constructivist grounded theory approach, I compared and contrasted themes that emerged from the data. This process allowed me to co-construct a theory of the empowerment process grounded in participants' interpretations of this phenomenon.

#### ***3.5.1 Study Population***

Post-treatment head/neck and breast cancer survivors were recruited to explore the meanings and processes of empowerment from their own perspectives. As noted in Chapter 1, head/neck and breast cancer are two types of cancer that present different social characteristics thereby establishing a possible range for the interpretive nature of empowerment. Given the distinctions in risks factors, post-treatment concerns and resources allocated to breast cancer survivorship compared to those with head/neck (Binkley et al., 2012; Molassiotis & Rogers, 2012; McQuestion et al., 2011; Tighe et al., 2011), questions arise as to whether empowerment

would be described similarly in these two populations. For example, would a head/neck survivor with difficulty swallowing and speaking describe empowerment in a comparable fashion to someone coping with sexual dysfunction as a result of breast cancer treatment? Exploring empowerment in two such groups with such disparate challenges provides a rich examination of a phenomenon that is routinely applied to all types of cancer.

### *3.5.2 Study Setting*

Post-treatment head/neck and breast cancer survivors were recruited from the Princess Margaret Cancer Centre (PM) at the University Health Network (UHN) in Toronto, Canada. The Princess Margaret Cancer Centre is the largest comprehensive cancer centre in Canada and one of the 5 largest cancer centres in the world. The Princess Margaret Cancer Centre offers comprehensive, multidisciplinary cancer care and expertise across the spectrum of cancer services. The Cancer Centre has 12 site groups, which includes clinics specific to head/neck and breast cancer treatment and survivorship care. Both clinics are dedicated to managing these cancers and offer comprehensive interdisciplinary care during and after treatment.

### *3.5.3 Sampling*

Purposeful sampling was used to identify head/neck and breast cancer survivors who were interested in exploring their experiences in managing the physical and psychosocial challenges they have faced throughout their illness. The following inclusion criteria was used to identify participants: a diagnosis of head/neck or breast cancer; within 3 months to 5 years post treatment; 18 years of age or older; able to describe their experience in English; interested in exploring and sharing their experience of managing the physical and psychosocial challenges

associated with diagnosis and treatment. Recurrent or metastatic cancer at recruitment; inability or refusal to provide informed consent and any form of cognitive impairment (as judged by clinicians) and/or the inability to carry out an interview were used as exclusion criteria. I focused on including head/neck and breast cancer survivors because I wanted to determine if there were any differences in the ways empowerment was experienced between those with these two types of cancer. The 3 months to 5 year post-treatment window was chosen because it takes into consideration the Cancer Care Ontario follow-up guidelines for breast and head/neck cancer.

#### *3.5.4 Participant Recruitment*

Participants were recruited in-person from the head/neck and breast cancer out-patient clinics. To identify potential participants, I worked with clinical staff and followed a series of steps to recruit participants. First, before I arrived in clinic, I reviewed appointment lists and electronic patient records (EPR) to identify potential participants. Patients who fell within the 3-month to 5-year post-treatment time frame, were not metastatic, and had not experienced a recurrence were identified. Accessing this information through EPR helped facilitate the identification of potential participants before I arrived in clinic.

Once potential participants were identified, I attended clinic when they were scheduled. While there, I reviewed my list of potential participants with the attending physicians. Potential participants who had difficulty speaking English, or who could not provide informed consent (for instance because of mental health challenges discerned by the physician), who had any form of cognitive impairment, or were otherwise unable to carry out an interview were screened out. Once eligible participants were identified, their physicians introduced the study using a prepared script and study information sheet. If patients were interested, I proceeded to approach them

during their appointment, with the physician's approval; I introduced myself, described the study, answered questions, and sought informed consent. If this was provided, I scheduled an interview at a mutually agreed upon time and place. In the case of potential participants who were unsure of whether they wanted to participate, I provided my contact information (email address and specified UHN phone number) for them to contact me at a later time. Please refer to Appendix A the consent form and study information document.

### *3.5.5 Sample Size*

In grounded theory, the size of the sample is based on theoretical saturation (Charmaz, 2014; Mason, 2010). However, it is difficult to predict what sample size will saturate a grounded theory. Sample sizes can range from 10-60 participants (Starks & Trinidad, 2007; Cresswell, 2013) and is influenced by a number of factors such as the heterogeneity of the sample, the scope and complexity of the social phenomenon, and the expertise of the researcher (Mason, 2010). As a doctoral candidate who was exploring a social phenomenon that is ambiguous, I anticipated that a larger sample would have been needed to reach theoretical saturation. In a content analysis of 560 PhD studies using qualitative approaches, Mason (2010) found that grounded theory studies had sample sizes as large as 87 participants and as low as 4 participants, with mean sample size of 32. Since I was exploring empowerment in two groups, those diagnosed with head/neck and breast cancer, I recognized that I would need enough participants in each group to establish both inter and intra group comparison. Inter and intra group comparison involved paying close attention to differences in how participants with head/neck and breast cancer talked about their illness experiences. Given concerns about feasibility in relation to doctoral research, I

aimed to recruit 15-25 participants dispersed across cancer of the head/neck and breast to do conduct this inter and intra group comparison.

My final sample included 22 participants, 13 head and neck cancer survivors, and nine survivors of breast cancer with one of these participants diagnosed with both types separated by a 10 year period. After transcribing and analyzing all interviews no differences between groups were identified. In addition, I found considerable repetition of the preliminary themes after nineteen interviews. Although repetition of preliminary themes should not be confused with theoretical saturation (Charmaz, 2014), I continued to test my themes with the remaining three interviews to confirm this repetition. I then doubled back to all earlier interviews to explore these themes further. In doing so, I discovered unique properties within these themes. After analyzing each interview again I concluded that I was no longer learning anything new about the data I collected. This point of a grounded theory is known as reaching data saturation.

Although data saturation continues to be a contentious aspect of the grounded theory method (see Aldiabat & Le Navenec, 2018; McPherson & Thorne, 2006), I continued to test my themes and their properties in each interview until I was confident I was no longer discovering any new properties. Other strategies to seek saturation could have been utilized such as interviewing participants a second time. I decided against using this approach because I felt that my interviews provided enough depth to build a grounded theory of empowerment. This decision was also made with the acknowledgement that cancer survivors are a vulnerable group. I did not want to burden participants with a second interview unless it was deemed crucial in the development of my grounded theory, given that the interviews were already on average 53 minutes in duration.

### 3.5.6 Data Collection

Charmaz (2014) underlines the need to collect rich data from a variety of sources. In this study, the sources of data included a participant demographic form, recorded and transcribed verbatim semi-structured face-to-face and/or over the phone interviews, and [field] notes based on my observations while interviewing participants.

*Demographic Form:* Demographic information was collected via self-report from participants before the interview began. The demographic form asked 14 questions pertaining to participant characteristics (place of birth; languages spoken; date of birth; sex; relationship status; living arrangements; level of education; employment status; current occupation; yearly household income; cancer diagnosis; date of original diagnosis; date of last treatment; types of cancer treatments). These participant characteristics were collected to gain an understanding of the population (sample) involved in the study to determine the heterogeneity of the sample to assist with assessing the transferability of the findings to other settings/populations.

*Interviews:* Interviews served as the primary means of data collection. To elicit participants' views, definitions and experiences of empowerment, I conducted semi-structured "intensive interviews." Charmaz (2014) defines intensive interviewing as gently directed open-ended and focused questions to get detailed responses that emphasize participants' meanings and experiences of a social phenomenon (Charmaz, 2014, p. 56; 85). This is accomplished by eliciting participants' stories while asking probing questions to gather detailed accounts of themes that emerge from the participants' narratives related to the social phenomenon under investigation.

For this study, I conducted one intensive interview (face-face or over the phone) with each of the 22 participants. Charmaz (2014) notes that unlike other types of qualitative research constructivist grounded theory places priority on theory development. Therefore, I was required to find a balance between maintaining a degree of control over interviews in order to ask participants directive questions related to the emerging themes of empowerment while simultaneously providing participants with open and flexible space to allow their thoughts and feelings to emerge during the interview. For example, I asked participants to speak openly about their illness experience. I paid close attention to their words and mannerisms. If something was raised that triggered an emergent idea, I wrote it down on a pad of paper and returned to the idea later during the same interview. Writing the idea down gave me the flexibility to allow participants' thoughts to emerge organically while also having the ability to ask directive questions about an emergent idea.

In-person interviews were hosted in a quiet room at the Princess Margaret Cancer Centre or at the ELLICSR Cancer Survivorship program located at the Toronto General Hospital. If desired by the participant, interviews were conducted over the phone, as not all participants felt well enough or wanted to travel to the Princess Margaret Cancer Centre or to ELLICSR for the interview. Interviews ranged between approximately 25 minutes and 90 minutes and explored emerging themes related to empowerment (e.g., control; autonomy; participation; self-management).

An interview guide was created to provide some structure for each interview (see Appendix B). Questions were kept broad and open-ended and included specific topics and subject areas to allow participants' thoughts and perceptions about empowerment to emerge openly. Topics included 3 main areas: 1) Life before the diagnosis - *What was your life like*

*before you were diagnosed with head and neck/breast cancer?; 2) The experience of being diagnosed and treated for cancer - Can you tell me about your experience being diagnosed and treated for head and neck/breast cancer?; 3) The experience of transitioning from treatment to post-treatment life - What was the process like for you when you finished your treatment? This was followed by directive questions about the emerging meanings and processes of empowerment (i.e. *Based on the experiences and challenges that you've expressed, what is your understanding of the word empowerment?*). These topics were based on my reading of the literature and my own experiences with the phenomenon. However, since constructivist grounded theory is an emergent design, the guide provided me with some flexibility to ask questions to explore any nascent themes concerning the experience. Therefore, my probing questions often varied over the course of the data collection and analysis process.*

*Field Notes:* I wrote field notes at the conclusion of each interview to capture my initial impressions of any emerging thoughts from my conversation with the participant. In addition, I wrote about how well I was able to connect with the participant and how that may have shaped what was shared during the interview. These notes were referred to when I was coding each individual interview to help me recall my initial thoughts and feelings. This type of recall gave me the point of departure to start coding each respective interview.

### 3.5.7 Data Analysis

All interviews were audio-recorded and transcribed verbatim noting pauses, silences and punctuation. To analyze each interview, I used the three-step iterative coding process of initial, focused and theoretical coding that is consistent with Charmaz's (2014) constructivist grounded

theory (2014). Before coding, I first listened to each interview as an entirety and made notes of my initial thoughts in the margins of each transcript. I then proceeded with coding.

Initial coding involved coding each word, line or segment to discover and link data with emerging themes. Focused coding involved comparing and contrasting these emerging themes with all other codes and relating them back to the data so I could organize themes into broader conceptual categories. For theoretical coding, I took what I believed to be the most significant categories to illuminate the relationships between data, codes, categories and themes. Theoretical coding allowed me to develop the scheme that became my theoretical model of the empowerment process.

Since initial, focused and theoretical coding is an iterative and flexible process, I was able to move between coding levels as I compared and contrasted all levels of data. As I proceeded, I referred to my observational notes written at the end of each interview, the responses from the demographic questionnaires, and the literature, to assist in seeking out relationships and meaning within the data. Emerging thoughts from this analysis were used to create questions for subsequent interviews to confirm or disconfirm my insights. This form of theoretical sampling allowed me to discover the most salient themes that were emerging from the data. Theoretical sampling continued until I was no longer learning anything novel about the emerging themes and categories. Therefore, through this iterative process data collection and analysis, I was able to compare and contrast participants' meanings of empowerment with my own emerging knowledge of the concept to co-construct a theory of empowerment grounded in the perspective of my participants. The qualitative software program Atlas Ti aided with the organization and coding of the interview transcripts.

In addition to the process of analysis, I also wrote brief accounts of each person's experience with cancer to compare with my emerging codes, themes and categories. Drawing on the words and mannerisms used by each participant during their interviews, I identified commonalities and differences. A summary of each account is included in Table 2 that highlights how each person experienced the illness.

### *3.5.8 Rigour*

Different procedures were used to ensure rigour in the construction of my grounded theory. I kept a reflexive journal to distinguish my own thoughts and feelings from those of my participants to ensure my emerging insights were based on the experiences of my participants and not solely a projection of my own thoughts and feelings. Included in this journal were entries specific to comparing how I was assigning meaning to my data (i.e., creating and organization codes into themes and categories) with the words used by each participant. This type of comparison helped ensure that my process of assigning meaning was grounded in the data.

In addition to keeping a reflexive journal, I wrote memos to explore the differences between units of data (codes, themes and categories) and their relationships in the overall process of empowerment. Memos took various formats. At times, memos were embedded into a reflexive journal entry when I was comparing my codes, themes and categories with the words used by participants. Memos were also written in the margins of my interview transcripts to capture my thoughts when I was reading and coding my data. At other times, memos were written as separate Microsoft Word documents. These documents included written descriptions about specific codes/themes/categories, tables that compared different codes/themes/categories, and visual diagrams that identified possible relationships between these units of data.

Finally, in addition to reflexive journal writing and memos, I wrote field notes at the conclusion of each interview to capture my first impressions from my interactions with each participant. Field notes were also meant to help me become aware of how my interactions with participants were shaping the co-construction of my findings. In constructivist grounded theory, researchers are subjective participants and co-creators of meaning with their participants. Therefore, they must pay close attention to the influence of their interactions with participants, which can affect knowledge shared and its interpretation. To accomplish this, I wrote notes about the interview setting, my body language, how I spoke to each participant and how participants interacted with me during the interview. Based on these notes, I explored different ways I could adjust my interactions with participants to elicit the types of responses I required to build my theory. An external audit trail was kept to track and provide rationale for these adjustments.

By engaging in these rigorous techniques, I sought out relationships and meaning in the data to make sure my insights were grounded in participants' experiences. These insights were continuously tested by re-entering the field by asking specific probing questions to discover the most salient themes that were emerging from the data. Through this iterative process of analysis, I was able to compare and contrast participants' meanings of empowerment with my own emerging knowledge of the concept to construct a theory of empowerment grounded in the perspective of my participants.

These procedures were based on Lincoln and Guba's (1985) criteria for producing qualitative research of high quality. These authors provide four criteria to establish rigour in qualitative inquiry. These criteria are: credibility, transferability, dependability and confirmability. To establish credibility, I stayed as close as possible to the words used by participants when analyzing and coding data and checked the theoretical construction generated

against participants' meanings of the phenomenon during interviews. I used reflexive journaling, memo writing and my field notes to articulate my personal views and insights as I built my theory to ensure that my findings were accurately representing participants' perspectives. To ensure transferability, I sought maximum variation by interviewing participants with varying demographic characteristics. As an aid to confirmability, I used my reflexive journal to understand how I my interpretation of the data compared with the words used by my participants in to ensure that my analysis represented their views rather than my own. Finally, for dependability, I kept an external audit trail to track all decisions made regarding the data collection and analysis process.

### ***3.6 Ethical Considerations***

Ethics approval was obtained from the University of Ottawa and from the University Health Network (UHN). The UHN is the clinical healthcare and medical research organization that owns and operates the Princess Margaret Cancer Centre.

#### ***3.6.1 Informed Consent***

All participants expressing interest in the study were asked to give written informed consent. As lead researcher, I reviewed the consent form with potential participants and answered any questions they had. Potential participants had as much time as they needed to think about their decision to participate in the study. Once they agreed, participants signed the consent form under the witness of the lead researcher. If written consent was not obtained in advance (e.g., I was contacted over the phone by a potential participant), verbal consent was obtained to

move forward with the study and a consent form was mailed to the participant and returned in self-addressed envelope.

### *3.6.2 Privacy & Confidentiality*

All information collected was kept in strict confidence. All data was coded by ID numbers and names and other participant identifiers were kept separate from the data collected. Pseudonyms replaced participant ID numbers for the purpose of publications. Access to raw data was restricted to research team members accessible only with protected password to computer data or locked paper files. As the Study Lead Investigator, I undertook to keep any personal health information and study data collected in a secure and confidential location for 10 years and then destroy it according to UHN Policy. Paper based data was stored in locked filing cabinets in a locked office. Data collected electronically (recordings and transcripts) was stored on secure password protected computers at the Toronto General Hospital. Electronic devices used to audio record interviews were wiped once the recording was safely and securely saved on the password protected computers at the Toronto General Hospital.

### *3.6.3 Benefits and risks for participants*

Participants did not directly benefit from their participation in this study. Rather, possible benefits of the study may have been a sense of helping others in a similar situation and/or contributing to research in this area. Information gathered throughout the study will help inform the researcher and the scientific literature on this topic, which may then guide the development of programs and supports for people completing treatment for cancer. The risks to the participants in this study were limited to possible psychological discomfort when sharing their

experiences. In such cases, the interview was paused and participants offered the option of continuing or terminating the interview, as well as the option for referral to the PM Psychosocial Oncology and Palliative Care (POPC) Program for professional support if desired. No participants accepted this referral. Participants were assured that their decision to participate, or not, would in no way affect their follow-up or future treatment and care at the hospital.

### ***3.7 Summary***

By taking a qualitative approach and using the constructivist grounded theory method, I was able to explore empowerment from the perspective of 22 cancer survivors to establish a substantive theory that outlines the processes associated with experiencing this phenomenon. As my reading of the literature highlighted, empowerment is a subjective concept that can take on different meanings depending on the individual, their circumstances and how they perceive the world around them. Given the subjective nature of the phenomenon, the constant comparative method and sampling techniques of constructivist grounded theory allowed me to explore variants in how each participant defined empowerment and the processes they underwent to achieve this experience. As my findings in the next chapter highlight, the notions of empowerment emerging from my analysis are complex and conflicting situating the phenomenon as a dynamic process participant's experienced as they moved between taking action associated with enhancing one's control over the management of their illness and a letting go of the "fight" by accepting one's new reality resulting in a more passive approach to one's care. By being reflexive and engaged in memo writing, I was able to confirm this understanding as I progressed with my data collection and analysis. Thus, my resulting theory represents a co-construction between my understanding of empowerment and the insights provided by my research

participants bringing clarity to a pivotal phenomenon in the post treatment management and rehabilitation of cancer survivors.

## **Chapter 4 Findings**

### ***4.1 Introduction***

Using a qualitative research approach and the grounded theory methodology in particular, 22 interviews were conducted and analyzed to illuminate the underlying social processes related to how someone with cancer might experience empowerment. The analysis of these interviews illustrated that participants felt empowered when they developed a sense of psychological strength and fortitude from struggling with and then overcoming the difficulties associated with being diagnosed and treated for cancer. Overcoming these struggles occurred in two concurrent dynamic and paradoxical ways – 1) Establishing control over the treatment, management, and impact of the illness on a person’s daily life as a means to circumvent an eroding and changing sense of self, and 2) Relinquishing control over aspects of the illness deemed irrepressible and incorporating those aspects into a new identity.

### ***4.2 The Co-construction of Meaning***

Before elaborating further, it is critical to situate these findings reflexively to consider the co-construction of meaning that is a hallmark of the grounded theory methodology I chose. The construction of my substantive theory of empowerment represents a cumulative process of confirming/disconfirming my emerging insights in each interview that I conducted. This type of theory building is aligned with the theoretical framework of this work, social constructivism.

In this study, my interactions with each participant played a fundamental role in the construction of my substantive theory. As discussed in Chapter 1, I have a particular understanding of empowerment that is embedded in my own sense of self. When co-creating

meaning with participants, I had to be aware of my own personal views of this phenomenon to ensure that my interpretation of the data was grounded in the ways participants spoke about their experience with cancer. The constant comparative method enabled me to explore and compare my own views with those of my participants to develop a shared understanding. This comparison is an illustration of the co-creation of meaning within a social-constructivist framework that shaped the findings of this study. Thus, my substantive theory represents the views and perspectives of my research participants in light of my notions of what I believe empowerment to be.

#### ***4.3 Participants: Demographic Summary***

I recruited a heterogeneous sample to achieve maximum variation across age, gender, marital and employment status, annual net income, and treatment type, as well as the length of time between treatment and post-treatment recovery (Table 1). The average age of participants was 54 years, the oldest being 68 and the youngest 26, with participants distributed over this age range. This variation was to ensure representation across age groups.

My sample included 13 individuals diagnosed of head/neck cancer (10 men and 3 women), 8 women diagnosed with breast cancer, and 1 woman who had a diagnosis of breast cancer followed 10 years later by a diagnosis of head/neck cancer. Overall, participants experienced an array of different types of cancer treatments, including chemotherapy, radiation, and surgery, with more than half receiving at least two or more of these types of modalities (13/22). On average, interviews occurred 17 months post-cancer treatment. However, time since treatment varied significantly with 6/22 participants completing treatment within the past year, 7/22 participants completing treatment over the past two years, 6/22 completing treatment over

the past three years, and one participant not disclosing this information. With that said, three participants fell outside of the 3-month to 5-year post-treatment inclusion criteria. One participant was still receiving radiotherapy and therefore not yet finished primary treatment, and two participants that were 10 and 16 years post-treatment, respectively. These participants were included in my study because it was only during their respective interviews that I discovered they fell outside of the inclusion criteria. Nonetheless, their inclusion permitted the expansion of my theoretical rendering of empowerment by exploring how empowerment might be understood by someone who still undergoing treatment or by individuals who have survived longer than 5 years. The interviews from these 3 participants illustrated that empowerment is an experience that begins to materialize at diagnosis and continues to evolve during treatment and post-treatment recovery.

The socio-demographic characteristics of my sample also varied. Most participants were married or lived with a life partner (15/22), with 7 individuals representing all other relationship categories: divorced/separated (2/22), never married (4/22), and widowed (1/22). Most participants had a university/college level education (16/22) and received an annual net income of at least \$61,000 per year (13/22). Of the remaining participants, 5/22 were earning an annual net income between \$30,000 and \$60,999 with an additional three individuals making less than \$30,000 per year. One participant chose not to disclose their income. Just under half of all participants were employed at the time I interviewed them (10/22), with all remaining participants retired (5/22), on disability leave (6/22), or pursuing full time education (1/22).

Table 1. Participant characteristics ( $N = 22$ )

<b>Participant Characteristic</b>	<b>Frequency (%)</b>	<b>Mean</b>	<b>SD</b>
Age (years)		54	13.2
Sex			
Male	10 (45.0%)		
Female	12 (55.0%)		
Cancer type			
Head/Neck	14 (63.6%)		
Breast	9 (40.9%)		
Education			
High school or less	6 (27.3%)		
College/university education or above	16 (72.7%)		
Employment status			
Employed	10 (45.5%)		
Retired	5 (22.7%)		
Unemployed/on disability	6 (27.3%)		
Student	1 (4.5%)		
Country of birth			
Canada	16 (72.7%)		
Other	6 (28.6%)		
Current relationship status			
Married/Life partner	15 (68.1%)		
Divorce/Separated	2 (9.1%)		
Never married	4 (18.2%)		
Widowed	1 (4.5%)		
Annual net income			
Over \$90,000	6 (27.3%)		
\$61,000 – \$90,000	7 (31.8%)		
\$30,000 - \$60,999	5 (22.7%)		
Below \$30,000	3 (13.6%)		
Prefer not to answer	1 (4.5%)		

#### *4.4 Participant Narratives*

By drawing on and comparing the words and mannerisms used by each participant to describe their experience with cancer, it became clear that cancer is an illness that impacts people in different ways depending on how they interpreted the threats associated with their diagnosis. For example, not every participant described their diagnosis or treatments for cancer as a significant life-threatening event. As a result, descriptions of the illness experience varied in depth and complexity. Even so, I identified within this variation a common narrative describing divergent ways a diagnosis of cancer can intrude on a person's daily life and personal identity<sup>2</sup>. This intrusion ranged from little to no influence to significant interference that prompted a struggle over the impact and management of the disease. It was from within these struggles that empowerment emerged as a complex, dynamic, and conflicting phenomenon.

The experiences of each participant are summarized in Table 2 to illustrate the different ways a diagnosis of cancer intruded on each person's daily life and personal identity as well as to provide a sense of the overall scope of my study. Below, I provide a more extensive account of two participant experiences to illustrate how empowerment is a phenomenon that people experience in different ways according to the intrusion of cancer upon each person's daily life and identity. I chose these two particular narratives to use as exemplars because they demonstrate a contrast between two concurrent dynamic and paradoxical ways empowerment was experienced.<sup>3</sup>

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<sup>2</sup> 'Personal identity' is being defined through a sociological (symbolic interaction) lens and refers to ways in which an individual defines, locates, and differentiates themselves from others (Charmaz, 1995; Frank, 1991).

<sup>3</sup> When discussing participant experiences throughout this chapter, I used pseudonyms rather than the real names of those that I interviewed as a way to maintain their anonymity. Names were chosen at random but associated with their self-reported gender identity. I also indicated the age of the participant and their diagnosis.

Table 2. Participant experiences

	Age	Type of Cancer	Treatment	Treatment Side Effects	Illness Experience	Key Empowerment Quotations
P1: Frank	53	Head/Neck	Surgery (Laryngectomy); Chemotherapy; Radiation	<ul style="list-style-type: none"> <li>Lives with a tracheotomy that impacts ability to eat, maintain weight, and speak</li> </ul>	<ul style="list-style-type: none"> <li>Endures chronic pain and has trouble walking</li> <li>Places strong emphasis on being strong and positive to cope</li> </ul>	<p><i>"Empowerment, how do I define it? It's mind over matter..."</i></p> <p><i>"...I think have a new beginning... Since I lost all that weight, I do have this opportunity right now of rebuilding my body in a nice way that any man at my age would want... That's the positive part about this..."</i></p>
P2: Steven	26	Head/Neck	Surgery (removal of cancerous lump; removal of lymph nodes)	<ul style="list-style-type: none"> <li>Nerve damage and loss of mobility in shoulder</li> </ul>	<ul style="list-style-type: none"> <li>Concerned with ability to play competitive sports</li> <li>Worried about stigmatization</li> <li>Lack of identification with 'cancer survivor' label</li> </ul>	<p>Participant: <i>"It [cancer] never got so serious that it was so life altering. It never got to that point so I don't feel like I am a "survivor". I could have had the flu for longer than I had this [cancer], you know what I mean?"</i></p> <p>Interviewer: <i>"So from this experience, is there anything that has been empowering?"</i></p> <p>Participant: <i>"Not really..."</i></p>
P3: Josh	57	Head/Neck	Surgery; Chemotherapy; Radiation	<ul style="list-style-type: none"> <li>Lives with a prosthesis that totally occludes an opening in the roof of mouth that was removed during surgery</li> </ul>	<ul style="list-style-type: none"> <li>Had difficulty with pain management</li> <li>Impressed with ability to cope with cancer</li> </ul>	<p><i>"Empowerment.. I will tell you one thing. I don't know how to define it but when you say "taking control", when you get diagnosed with cancer you lose all control... but once you crawl out of this and you get a good prognosis you feel like your life is back... Going back to a normal routine is a big help..."</i></p> <p><i>"Basically my life is almost all back to normal but I have to live with this thing in my mouth... But I got used to it and I figured it out..."</i></p>

	Age	Type of Cancer	Treatment	Treatment Side Effects	Illness Experience	Key Empowerment Quotations
P4: Tatianna	35	Head/Neck	Surgery; Radiation	<ul style="list-style-type: none"> <li>Experienced late effects from radiation treatment</li> </ul>	<ul style="list-style-type: none"> <li>Unable to fulfill role as a mother of two young children</li> <li>Felt concerns were being ignored by oncologists</li> </ul>	<p>“... this situation [cancer] has been very hard on me because it showed me that I can't control anything... I am trying now to take one day at a time but it's hard because if I was older it would be a lot easier... Because my kids are so young so I think that if I was over a certain age, I would worry less about the future and try to enjoy life more...”</p>
P5: Paul	65	Head/Neck	Surgery; Radiation	<ul style="list-style-type: none"> <li>Suffered nerve damage from removal of cancerous lump from the inside of cheek</li> </ul>	<ul style="list-style-type: none"> <li>Lives with an altered appearance</li> <li>Feels lucky and takes comfort in never being sick before</li> </ul>	<p>“Well I had no taste. My eye drooped. I could not open or close the eye. And if you could look at me. God, I was probably frightening children... But I can't let this thing control me... So I said the hell with it. I put on a pair of sun glasses and go! And that's what I did”.</p>
P6: Betty	55	Head/Neck	Surgery (Laryngectomy)	<ul style="list-style-type: none"> <li>Had vocal chords removed and uses a 'voice box' to speak</li> </ul>	<ul style="list-style-type: none"> <li>Experienced stigmatization</li> <li>Cancer has not impacted sense of self or daily life</li> </ul>	<p>“I would say that's what I am. I empower myself and I keep going. I am a strong person and I know it. I think it comes from living with 4 brothers to be honest.”</p> <p>“that word [cancer] can be very scary because you automatically think you are going to die... But you have to deal with the treatments... and figure out what's most important to you and then enjoy it...”</p>
P7: Daniel	66	Head/Neck	Chemotherapy; Radiation	<ul style="list-style-type: none"> <li>Suffered complications from treatments including a stroke</li> </ul>	<ul style="list-style-type: none"> <li>Side effects of pain medication lead to suicidal ideations</li> <li>Amid these complications, takes strength in his will to live</li> </ul>	<p>Interviewer: “So based on your experience, would you say you've been empowered?”</p> <p>Participant: “Absolutely... Because even though I am not complete anymore, I still have my dignity, and I still want to live”.</p>

	Age	Type of Cancer	Treatment	Treatment Side Effects	Illness Experience	Key Empowerment Quotations
P8: Sharon	67	Head/Neck & Breast	Surgery (Mastectomy); Chemotherapy; Radiation	<ul style="list-style-type: none"> <li>• Drastic weight and hair loss</li> <li>• Hot flashes</li> <li>• Debilitating weakness to the point where she required help to walk stairs.</li> </ul>	<ul style="list-style-type: none"> <li>• Described both cancers as significant life changing events that altered sense of self</li> <li>• Felt stranded by healthcare system when transitioning into post-treatment care</li> <li>• Retired from vocation due to impact of cancer</li> </ul>	<p><i>“For me it [cancer] gave me strength. It gave me a positive outlook that even though it was such a terrible experience, I could actually do something good with it from something so terrible. ... It empowered me to talk to people about this. It’s a little better life actually. It gives you a totally different perspective on life...”</i></p>
P9: Jason	51	Head/Neck	Surgery	<ul style="list-style-type: none"> <li>• Difficulty eating and speaking after surgery</li> </ul>	<ul style="list-style-type: none"> <li>• Drawn out period (3 years) to be diagnosed</li> <li>• Hid impact of illness from others</li> <li>• Adopted a more empathic view of life</li> </ul>	<p><i>“I guess to me empowerment is the belief that you have control and that you can make a change...”</i></p> <p><i>“... For me, it [cancer] changed my perspective on a lot of stuff... things come from out of the blue and to me it widens my appreciation for what can happen and what other people deal with...”</i></p>
P10: Joe	64	Head/Neck	Surgery	<ul style="list-style-type: none"> <li>• Removal of a portion of his tongue</li> <li>• Changed the way he speaks</li> </ul>	<ul style="list-style-type: none"> <li>• Impact of illness shaped by vocation as a police officer and past experience with illness</li> <li>• Quit smoking as a result of surgery and is proud of this accomplishment</li> </ul>	<p><i>“Being a cop you deal with death all the time... So you get really used to death.”</i></p> <p><i>“... My personal feelings all a long were sooner or later I was going to get cancer... My mother had cancer... my father had cancer... my sister died of cancer... so I just kind of figured so be it...”</i></p>
P11: Fay	68	Breast	Surgery; Radiation	<ul style="list-style-type: none"> <li>• Described experience with cancer as uneventful</li> </ul>	<ul style="list-style-type: none"> <li>• Did not feel traumatized when diagnosed because of how well her family has dealt with illness</li> <li>• Considered fortunate that chemotherapy was not needed</li> </ul>	<p><i>“I would not use the word ‘shock’ [from being diagnosed]... I would say it would be a good 60% that my family has dealt with it [cancer] and we came through...”</i></p> <p><i>“... I remember thinking that I was so glad that I did not have to have chemo because I have heard so many bad things ...”</i></p>

	Age	Type of Cancer	Treatment	Treatment Side Effects	Illness Experience	Key Empowerment Quotations
P12: Maria	37	Breast	Surgery; Chemotherapy; Radiation	<ul style="list-style-type: none"> <li>• Existential crisis</li> <li>• Exhaustion</li> </ul>	<ul style="list-style-type: none"> <li>• History of benign breast cysts</li> <li>• Blames herself for illness</li> <li>• Now sees world in a different way</li> </ul>	<p><i>“You don’t see life the same way after cancer. I am not sure but I think I can manage conflicts or challenges better. I don’t worry much about things. If I face a challenge I know I will come out with a solution.”</i></p>
P13: Stephanie	27	Breast	Surgery (double mastectomy); Chemotherapy; Radiation; Hormone therapy	<ul style="list-style-type: none"> <li>• Still in active treatment</li> <li>• Chemo brain</li> <li>• Fatigue</li> <li>• Pain</li> </ul>	<ul style="list-style-type: none"> <li>• Illness has put a strain on marriage and delay on career progression</li> <li>• Opted for breast reconstructive surgery and struggles with the reasons behind decision</li> </ul>	<p>Interviewer: <i>“Out of your experience, has anything been empowering to you?”</i></p> <p>Participant: <i>“No. I don’t, I’m not there yet. I think I will eventually get there. But I was really strong before [cancer] and now I’m really weak. And people say, you know, you’ve accomplished so much and I don’t feel that way.”</i></p>
P14: Jackie	46	Breast	Surgery (partial mastectomy); Chemotherapy; Radiation	<ul style="list-style-type: none"> <li>• Limited mobility from peripheral neuropathy,</li> <li>• Erratic menstrual cycle</li> <li>• Constant fear of recurrence</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulties managing the physical and emotional impact of treatment</li> </ul>	<p><i>“It [cancer] is empowering. I had the courage... even though it was a very hard journey, I’m happy... I feel like it’s a huge burden that’s been lifted. I feel a lot freer that I’m on my journey to recover.</i></p>
P15: Tom	66	Head/Neck	Surgery	<ul style="list-style-type: none"> <li>• Lacks sensation in mouth and is always in constant thirst</li> <li>• Surgery left a noticeable scar on neck</li> </ul>	<ul style="list-style-type: none"> <li>• Recovering alcoholic, which has impacted his reactions to cancer</li> <li>• Purposely hides scar on neck with a beard</li> </ul>	<p><i>“I am a recovering alcoholic and I haven’t had a drink in over 18 years. So I have a different mindset...”</i></p> <p><i>“When I was diagnosed it was sort of like, well, there’s only one person to blame for this cancer and that’s the guy who did all the smoking and the drinking... This is what, this is what’s going to happen and the sooner you get on board...”</i></p>

	Age	Type of Cancer	Treatment	Treatment Side Effects	Illness Experience	Key Empowerment Quotations
P16: Billy	65	Head/Neck	Surgery (Laryngectomy); Radiation	<ul style="list-style-type: none"> <li>Lives with tracheotomy and uses voice box to speak</li> </ul>	<ul style="list-style-type: none"> <li>Frustrated by difficulties with speaking</li> <li>Feels stigmatized by wife</li> </ul>	<p>Interviewer: “<i>Has anything been empowering for you?</i>”</p> <p>Participant: “<i>I don’t think so... I mean... I don’t think it’s made me stronger. Maybe it’s made me more aware... I mean, how could this happen? My buddies, they go ‘you’ve never smoked’. And I said ‘See, anyone can get it’.</i>”</p>
P17: Ann	66	Breast	Surgery; Chemotherapy; Radiation	<ul style="list-style-type: none"> <li>Nausea</li> </ul>	<ul style="list-style-type: none"> <li>Self-blame for diagnosis</li> <li>Tried to keep a sense of normality during and after treatment</li> <li>Fear of stigmatization</li> <li>Difficulty accessing care during treatment</li> </ul>	<p>“<i>So I guess with the chemo, it wasn’t that the chemo was, you know, that, that I couldn’t function, in fact I did quite well...</i></p> <p><i>... I was just really mindful and just keeping as much semblance of order for my kids as possible, right?..</i></p>
P18: Tina	68	Breast	Surgery; Radiation	<ul style="list-style-type: none"> <li>Suffers from minor pain managed through medication</li> </ul>	<ul style="list-style-type: none"> <li>Spiritual beliefs tempered reaction when diagnosed</li> </ul>	<p>Interviewer: “<i>Has anything been empowering for you through your experience?</i>”</p> <p>Participant: “<i>No, I love to work, I love to gardening, I love to cook. I have little pain</i>”</p>
P19: Erin	48	Breast	Radiation	<ul style="list-style-type: none"> <li>Hampered by chronic pain and fatigue</li> </ul>	<ul style="list-style-type: none"> <li>Fear of losing job when diagnosed</li> <li>Difficulty transitioning into post-treatment care</li> </ul>	<p>“<i>Has anything been empowering? I know, I always, I always like the adage that what doesn’t kill you makes you stronger. And that’s what I try to live by. I’ve been through adversity, but I’m not going to let it beat me...</i>”</p>

	Age	Type of Cancer	Treatment	Treatment Side Effects	Illness Experience	Key Empowerment Quotations
P20: Gerard	61	Head/Neck	Surgery (Laryngectomy)	<ul style="list-style-type: none"> <li>Chronic pain</li> <li>Lethargic from pain medication</li> <li>Difficulty speaking and eating</li> </ul>	<ul style="list-style-type: none"> <li>Difficulty speaking and breathing impacting participation in day to day life</li> <li>Takes solace that some activities (lifting weights and playing golf) are not affected</li> <li>Feels a stronger connection to his faith as a result of his cancer</li> </ul>	<p><i>“Last week, my wife lit some candles for me. She went back inside and I went to bed, but the candles were still lit. She said, ‘Why did you keep the candles going?’ and I said, ‘I can’t blow them out’ and she laughed.”</i></p> <p><i>“I was terrified of going through the surgery and what my life might be like after the surgery. So I, I didn’t pray for the cancer to go away, I prayed that I could have the strength to get through it... And I distinctly remember lying in pre-op, I hadn’t been sedated at that point, but being completely calm... And I can’t give any explanation other than the hand of God...”</i></p>
P21: Lizzy	68	Head/Neck	Surgery (Laryngectomy)	<ul style="list-style-type: none"> <li>Re-learned to speak</li> </ul>	<ul style="list-style-type: none"> <li>Constant exposure to illness through friends and colleagues which tempered reactions when diagnosed</li> <li>Takes pride in sense of strength and resiliency</li> </ul>	<p><i>“Dr. X was very positive and he said they would be taking a portion of my tongue... but after an MRI they thought because it was so close to the saliva gland, they would take that as well. But I didn’t they were going to take it. They basically cut across my throat to remove it, which left me with like a turkey neck... So that was a surprise, but I learned to deal with it”.</i></p>
P22: Sara	49	Breast	Surgery	<ul style="list-style-type: none"> <li>Suffers from migraines believed to be caused by adjuvant therapy</li> </ul>	<ul style="list-style-type: none"> <li>In constant fear of uncertainty</li> <li>Fear of stigmatization</li> <li>Re-prioritized life as a result of illness</li> </ul>	<p>Interviewer: <i>“Has any of your experience been empowering for you?”</i></p> <p>Participant: <i>“For sure... It [cancer] has made me much more confident in who I am... I’ve always been a physically active person and I can’t do a lot of the things I could do, and so, you have to be okay with those changes”</i></p>

*Example 1: Gerard*

Gerard is 61 year old retired public service employee. He was diagnosed with head/neck cancer the year prior to our interview and required surgery (a laryngectomy) to treat his cancer. The laryngectomy left a permanent opening in his neck/throat creating a separation of the airway from the mouth, nose, and esophagus. Gerard now requires a Larybutton to help him speak, eat, and breathe.

Coming from a family lineage of no cancer and little history of chronic disease, Gerard was shocked when he was diagnosed. Before cancer, he considered himself in relatively good health for a man of 60 years. Being aware of the risks associated with cancer and having a perpetual fear of the asymptomatic characteristics associated with the disease, Gerard lost 30 lbs just prior to his diagnosis as a way to take preventative measures and to live a healthier life. To his dismay, he was diagnosed with cancer.

In addition to Gerard's shock, he was devastated when a laryngectomy was proposed as the primary mode of treatment, describing the moment as the day "my world came to an end". This reaction, as he explained during our interview, was based on a disturbing experience when, as a child, he encountered a man who had a tube lodged in his throat and suffered from a speech impairment, both a result of the same cancer and treatment.

Now cancer-free, Gerard lives with the consequences from his laryngectomy. The surgery has altered the way he breaths and his ability to speak, smell, and taste. These changes, albeit physical, permeate other areas of his life and are evident in the way he describes his inability to fully participate in taken-for-granted social behaviours such as blowing out candles, enjoying a glass of wine, and being able to engage in conversation. Furthermore, because of the anatomical changes to Gerard's breathing, he can no longer fully participate in his post-

retirement passion of carpentry. Typical gauze masks used to protect against the harmful dust and residue from this type of activity are no longer effective. Thus, in order to participate in this activity, Gerard invests time and resources innovating new ways to protect himself. He has yet to discover a suitable solution, and this appears to be a source of frustration for Gerard:

... One of the key concerns was my woodworking, that before surgery I could wear a regular gauze mask... Well, there's no method of filtering the dust for my situation now... I've tried to modify a regular type of mask to fit over the stoma, but that didn't work... I didn't expect the mask to be so difficult...

However, even amid this frustration, Gerard feels empowered. When I asked Gerard to describe if any aspects of his experience with cancer proved to be a source of empowerment, he said the following:

I hear so many stories about people dealing with so many types of hardships that I haven't experienced... So, I consider myself so fortunate. The fact that I was able to work out again... able to lift more weights than I was pre-surgery... and the fact that I can still go out and play golf and still blow everybody away! My lifestyle has not really changed except for my ability to talk...

Thus, compared to other people's experience with cancer, Gerard's ability to establish a certain level of control over the impact of his illness to circumvent any significant lifestyle changes has proven to be a source of pride and psychological strength that he associates with being empowered. He later stated in the interview that empowerment to him was "being able to do things by yourself, and not inconveniencing somebody else. Just having the authority to deal with it yourself".

Yet, even so, Gerard also acknowledged certain consequences of his illness that cannot be controlled. When referring to his difficulties speaking, Gerard noted the following: "There is no fix for this. This is the way you're going to be the rest of your life and my response of 'ok'...". This is an acknowledgement that also seems to have contributed to Gerard's emerging sense of empowerment:

...six months ago, seven months ago, I'm not the same person as I am today. That person would not have been able to deal with the surgery and the ultimate loss. I mean mentally, I didn't feel I was strong enough for that... I don't know why, but I've never had as positive an attitude about things. But I do now...

This example demonstrates that Gerard's emerging sense of empowerment seems to be coming from two distinct but simultaneous processes. The first process is associated with Gerard's ability to establish control over the impact of the illness as a means to circumvent a change over an eroding sense of self by still being able to engage in activities that brought him meaning before his diagnosis. At the same time, Gerard also relinquishes control over aspects of the illness he deemed irrepressible (his ability to talk) and incorporates this aspect into a new and 'empowered' identity, reflected in his newfound strength and positive attitude. These two conflicting processes of taking and relinquishing control form the basis of Gerard's emerging sense of empowerment.

Gerard's process of empowerment is also contingent upon two critical factors: 1) interpreting his diagnosis of cancer and its treatments as a threat to his sense of self and participation in day-to-day life; and 2) his ability to overcome these threats. Gerard draws on his family history, memories from his childhood, and what he observes in the experiences of others with cancer to determine how the illness threatens his day-to-day life and sense of self. For example, Gerard's unexpected diagnosis prompts a crisis because of the way he perceives his risks associated with cancer and his fears surrounding its treatments. However, as Gerard experiences his unique challenges, he engages in the dynamic and conflicting process of determining what aspects of his illness he can and cannot control. Gerard's success in establishing control and his ability to acknowledge and accept the limits associated with his healing represents his journey towards empowerment.

*Exemplar 2: Maria*

Maria is a 37-year-old Mexican-born Canadian citizen who immigrated to Canada independent from her family and friends in the mid-2000s. She was diagnosed with an aggressive rare form of breast cancer in 2012, at the age of 33. Her treatments included chemotherapy, radiotherapy, and a double mastectomy. Once her treatments were completed, she opted for breast reconstructive surgery.

Although Maria found her treatments physically and mentally difficult to endure and access to healthcare in Canada as a foreigner a point of contention, she spent our interview describing what can be best depicted as a crisis prompted by her belief that she was, in part, to blame for her illness. For instance, Maria had a continuous fear of getting cancer propagated by a history of developing non-cancerous breast cysts. Her inability to control this fear, Maria believes, contributed to her diagnosis stating: "... I've always been afraid that I was going to get breast cancer, but you should never have those thoughts because I believe you attract those ideas... I honestly think your thoughts become reality".

In addition to this belief, in the years leading up to her diagnosis Maria began feeling psychologically and physically unwell. Being overly obsessed with living a consumeristic lifestyle and unable to find meaning in her way of life, Maria felt a disconnect between her thoughts, feelings, and behaviours. Using phrases such as "I was completely broken inside" to describe how this disconnect made her feel, Maria showed signs of guilt and blame that it was her inability to address her poor state of being that contributed to her illness. Her use of tone and choice of words in the following quote reflects this belief: "How come I didn't notice [the lump]? Seriously!? I was so caught up in life that you even forget your own body!". It was from within this sense of self-inflicted illness that Maria began to perceive her cancer not as an

intrusive threat, but as a vehicle to purge and heal her poor sense of self. She noted the following:

...before my diagnosis I had a job and looked nice and looked well, but I was not feeling well inside... And I feel like the ailments [the cancer and the side effects of treatment] took all that away... once everything [cancer treatments] had finished, I felt like someone pulled something from my body. All the bad stuff went away and it's made me so clean spiritually and physically...

This purge was the epitome of Maria's emerging sense of empowerment.

Thus, similar to Gerard's experience with cancer, this exemplar illustrates how Maria draws on her beliefs, perceptions, and past experiences with the illness to determine how her diagnosis impacted her sense of self and participation in day-to-day life. For Maria, being diagnosed with cancer made her realize that it was her obsession with living a consumeristic lifestyle that led to her poor sense of self that contributed to her diagnosis. This type of realization was the beginning of Maria's emerging sense of empowerment. Her belief that her lifestyle and poor sense of self caused her own illness allowed her to fully embrace and use the illness and its treatment as a vehicle to re-adjust and create a new and empowered sense of self and identity.

However, Maria and Gerard's experiences are also different. Unlike Gerard, who took control over aspects of his illness to allow him to participate in activities that brought him meaning before his diagnosis, Maria appears less concerned with this type of control. Because Maria was unhappy with her life before her diagnosis, it is safe to assume that Maria felt little need to save an eroding or changing identity that brought very little meaning or satisfaction to her life. Thus, rather than attempt to control and circumvent the impact of the disease, Maria chose to fully embrace the hardships associated with her illness. This experience, when compared to Gerard's encounter with cancer, illustrates that empowerment is a phenomenon that

people experience differently, depending on the meaning assigned to their illness experience and how they interpret its impact.

Nevertheless, even with these noticeable differences, common across Gerard and Maria's experiences are examples that illustrate two different and, at times, dynamic and paradoxical ways empowerment can emerge. It can emerge when an individual is able to take control over the impact of their illness by maintaining or re-establishing a semblance of their pre-illness self during or after their cancer treatments. Yet, empowerment can also emerge when the individual accepts, embraces, and incorporates the hardships from the illness experience into daily life as a means to improve upon a sense of self and identity. Combined, these two processes of empowerment form the basis of this grounded theory. These processes are: 1) establishing control over the treatment, management, and impact of the illness on a person's daily life as a means to circumvent an eroding and changing self; and 2) relinquishing control over aspects of the illness deemed irrepressible and incorporating those aspects into a new and 'empowered' identity.

#### ***4.5 The Model of Empowerment***

##### *4.5.1 Overview of the Model*

The process of empowerment (Figure 3) begins with the diagnosis of cancer and the interpretation of the threatening elements of the illness experience. In this context, a threat is defined as any element of the illness experience that intrudes on a person's daily life and sense of self. Most participants interpreted their diagnosis as a threat. In circumstances when cancer was perceived to be less of a threat, controlling the impact became an unnecessary action making

empowerment a meaningless and redundant process. Thus, 'perceiving cancer as a threat' became the requisite core category of this substantive theory. Once cancer was perceived as a threat, participants dynamically moved between the two paradoxical processes of empowerment.

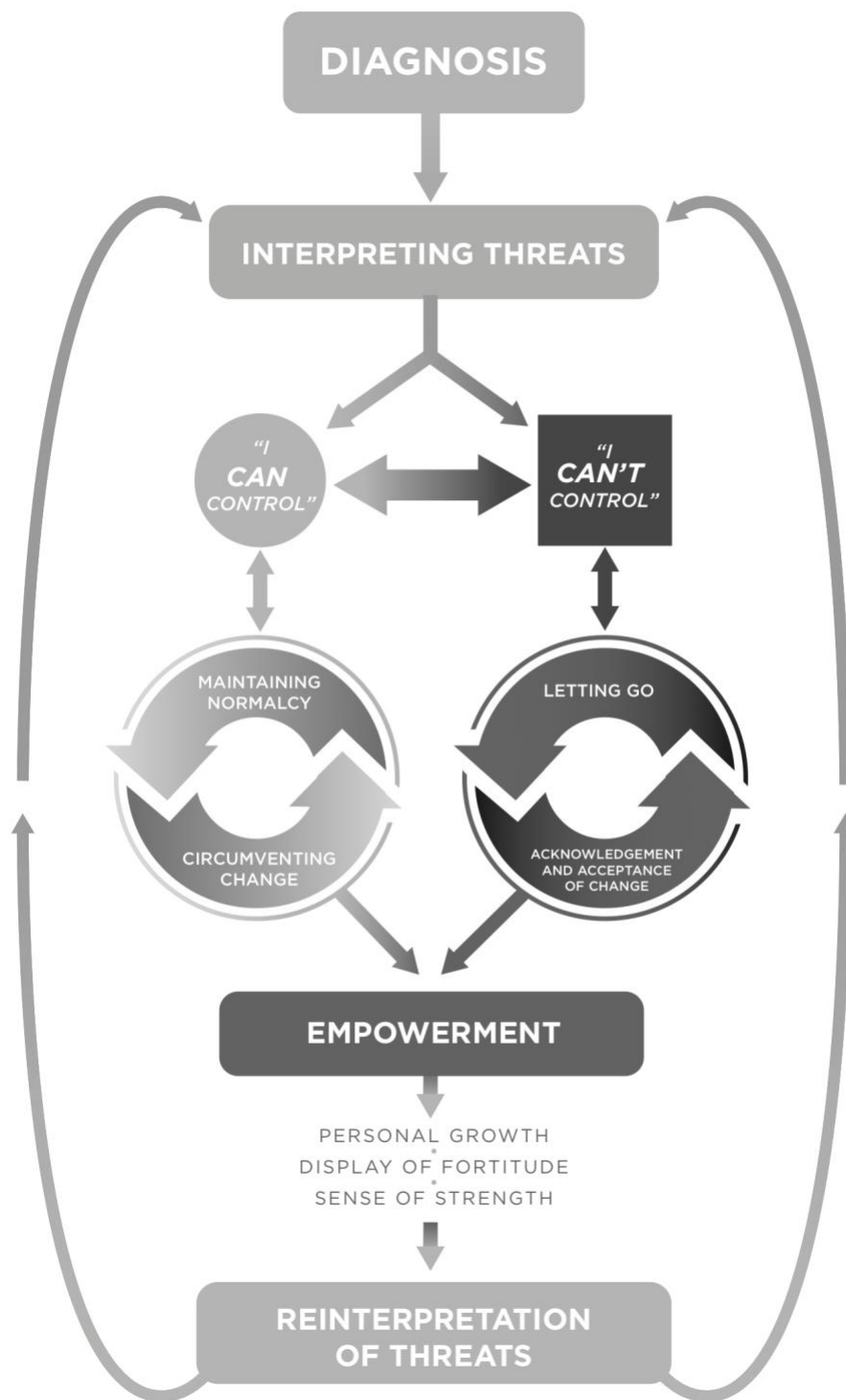
The first paradoxical process occurred when participants felt that they had successfully established control over their health and well-being. Participants deemed themselves in control when they were able to maintain a sense of normalcy and circumvent any change to their daily life amid the challenges they might have endured from being diagnosed and treated for cancer. This ability to be in control provided participants with a sense of fortitude, strength and personal growth from enduring cancer without any significant changes to their life or sense of self. Participants defined this experience as empowering.

The second paradoxical process occurred participants came to the conclusion that there were certain aspects of their illness that could not be controlled. To adapt, they had to let go of the idea of being in control and then accept and acknowledge that they needed to change in order to re-establish their sense of themselves in their daily life. When successful, participants also defined this alternative process of letting go (no control) empowering. Letting go and acknowledging and accepting change also provided participants with a sense of fortitude, sense of strength and personal growth from being able to adapt to their circumstance from enduring the threats posed by being diagnosed and treated for cancer.

At times the two paradoxical processes of empowerment were experienced concurrently as participants engaged in different behaviours to learn what they could and could not control. As they engaged in these two processes and began to develop a sense of fortitude, sense of strength and personal growth, they began to re-interpret the threats associated with their illness.

They no longer saw cancer as simply as a threat but as an experience that led to a sense of empowerment.

Figure 3. The model of empowerment



In the sections below, I describe each aspect of this rendering of empowerment beginning with the core category: perceiving and experiencing threats associated with cancer.

#### *4.5.2 Perceiving and Experiencing Threats*

For most participants, a diagnosis of cancer was enough of a threat to act as the catalyst to begin the process of empowerment while, for others, it was not the initial diagnosis *per se* that was threatening, but rather the prospect of undergoing cancer treatments. In addition, some individuals expressed that it was not until they either encountered barriers to accessing healthcare or experienced treatment side effects that the impending reality of having a serious illness became a concern. These variations suggest that the ways in which people perceive and experience threats associated with cancer are important when considering how empowerment emerges from the illness experience. For example, Betty (55-year-old head/neck cancer survivor) was adamant that her diagnosis of larynx cancer had very little impact on her life in spite of having her vocal chords surgically removed. Now requiring an assistive device (a voice box) to speak, Betty stated: “I am a strong person and I know it. I think it comes from living with four brothers. One of them is 16 years older. And four brothers don’t teach you how to ride a bike, they teach you how to box”. Already possessing of a sense of strength when she was diagnosed, it appears Betty pushed through the challenges associated with her illness without developing any noteworthy sense of accomplishment and therefore did not feel significantly empowered from her experience, stating “the only thing it [cancer] has done is strengthen my faith”.

Betty’s choice of words to describe the impact of her illness is in stark contrast to specific phrases used by other participants who described their experience with cancer as more life-changing. For example, Maria (38-year-old breast cancer survivor) described surviving cancer as “an awakening... it changed completely the way I see life”. Similar language was used by Jackie

(46-year-old breast cancer survivor), Sara (49-year-old breast cancer survivor), and Gerrard (61-year-old head/neck cancer survivor), who each described their illness as having a great impact. For example, and as noted above, Gerard describes the days after being diagnosed as the moment his “world came to an end” and that going through cancer had a drastic impact on his life by making him feel stronger and more courageous, stating:

... just more courage. I don't know. I do know that six months ago, seven months ago, I'm not the same person as I am today. That person would not have been able to have dealt with the surgery and the ultimate loss...

Other participants such as Tom (66-year-old head/neck cancer survivor), Lizzy (68-year-old head/neck cancer survivor), and Fay (68-year-old breast cancer survivor) described their own experience with cancer with much less intensity. For example, Tom noted that his struggles as a recovering alcoholic and raising a daughter with cerebral palsy tempered his reactions to his diagnosis and treatments for head/neck cancer:

...I can't say that it [diagnosis of cancer] was a shock. I mean, I can't blame anybody for this. It's not bad luck, it's nothing. I did all these crazy things [drinking] and this is the consequence. We also have a daughter who was three months premature and she has cerebral palsy. So I've been dealing with that for 29 years and learning about the ups and downs and that there's nothing that you can do about it. This is what it is and the sooner you get on board, the easier life's going to be... (Tom)

In comparison, Lizzy and Fay had a tempered reaction their diagnosis from witnessing many friends, colleagues, and family members who survived and coped well with the illness. These types of interactions tempered their reactions:

I was surprised but I don't know if I would use the word 'shock'. I was surprised but I looked on the bright side. See there is cancer in my family on both maternal and paternal side and I would say a good 60% of my family dealt with it and we came through. Although Netta and Rose, they died quite young, but of colon cancer. Colon cancer would have scared me. But somehow the breast cancer didn't because I think I've been exposed. Even friends and other people, actually even one male cousin, who had breast cancer and they came through. (Fay)

Similarly, Tina (68-year-old breast cancer survivor) also had a subdued reaction that emerged from her religious beliefs: “I’m not scared... I am a strong believer in god”. The similarities and differences between participants show how the impact of cancer varied depending on how each person interpreted the threats of their illness.

However, even amidst the different interpretations, common elements in each person’s illness experience related to how threats were perceived. As participants encountered any possible threat from their illness, they constantly reflected on the severity of their circumstances by comparing the gravity of their situation to that of others. As one participant noted:

I’ve never been sick a day in my life... I am 68 and you know I’ve got that far without any problems. I have friends riddled with this or that. They’ve always had this problem or that problem, and I was very fortunate. I was blessed I did not have any of that. So you know, I thought, how can I complain?

(Paul, 68-year-old head/neck cancer survivor)

Even if Paul feels fortunate and perceives his illness as less significant in comparison to the experiences of others, Paul’s head and neck cancer surgery resulted in nerve damage to the left side of his face causing facial paralysis and an altered appearance:

... Well I had no taste. My eye drooped and I could not open or close the eye. And if you could look at me, god I was probably frightening to children. My face was pulled over like that. So I was really self-conscious about that...

Comparatively, another participant stated: “I felt this [cancer] was a lot simpler than other people’s experiences. So that’s why I said I don’t feel like a survivor either, because my experience was so simple” (Steven, 26-year-old head/neck cancer survivor). For Steven, his cancer surgery involved the removal of lymph nodes in his neck, resulting in nerve damage that caused limited range of motion in his shoulder, all adding up to concerns about his ability to play competitive baseball. In addition to participating in this leisure activity, Steven’s surgery left a noticeable scar on his neck, provoking fears that people may look at him differently:

I do have something to talk about when people ask me about my scar. But I don't want to talk about it. The only thing that affects me a little bit is the insecurity about people feeling sorry for you... I don't want people looking at me like I've been shattered and broken down.

But even with this type of threat, Steven, like Paul, brushes off the severity of his cancer because, in hindsight, he views his illness as less severe when compared to other people with cancer:

I look at it to be relative to what other people go through when they deal with the scary word of cancer. A lot of other people, it claims lives and it throws other people off. I sit around in the waiting room and I see people coughing and I see people who are really sick. But then I look at mine [his cancer] and I say 'God damn that was simple'!

In summary, the severity or threat of the cancer diagnosis was established through comparisons to life experiences, the cancer experiences of others, and the perceived severity of cancer. Such deliberation was the point of departure for the processes of empowerment. While most participants interpreted their diagnosis as a threat, those who had a tempered reaction were less likely to develop a sense of empowerment. Betty, Fay, Tina are examples of participants who did not develop a strong sense of empowerment when compared to other participants such as Maria, Gerard, Sarah, Steven and Paul, who perceived their diagnosis as a significant threat to their sense of self and participation in daily life. It was from within this threat that empowerment emerged.

Table 3 provides examples of my progress from initial coding to higher-level focused coding to define this core category. In brief, I purposely highlighted data segments from three participant interviews (P9, P22, P14) to demonstrate different ways that individuals experienced their cancer as an intrusive threat. Sources of these intrusive threats varied, but the most commonly reported challenges were associated with changes in one's appearance, shifts in social roles, the inability to participate in meaningful daily activities, loss of physical function, feeling

stigmatized, living with uncertainty, and managing symptoms. These experiences were over and above the strains associated with accessing timely healthcare. Table 3 highlights some of these intrusions. When experienced, these intrusions were the catalysts that propelled each individual to move dynamically between the two paradoxical pathways towards empowerment.

In the following section, I move beyond consideration of the threats associated with a diagnosis to explore one of the two key dynamic empowerment processes – taking control.

#### *4.5.3 'I Can Control'*

For participants, taking control was triggered by distress and a sense of helplessness that followed reflection on how their identity or ability to participate in day-to-day life had been threatened. To address these threats, participants took control in two overlapping dynamic ways: 1) Trying to maintain a sense of normalcy to every-day life and; 2) Attempting to circumvent change to their sense of self. Participants used different strategies to take control in these two ways. They did so by: 1) Seeking support from health professionals; 2) Advocating when their needs were not being met and; 3) Seeking support from others; 4) Taking precaution when disclosing aspects of the illness to other people; 5) Incorporating the impact of the illness into daily life. Empowerment emerged when participants were successful at taking control in these ways.

Table 3. Perceiving cancer as an intrusive threat

Data	Coding		Conceptualization
	<u>Initial</u>	<u>Focused</u>	
<p>P9: One of the biggest fears that I had was how well I would be able to communicate after knowing that they were taking a chunk of my tongue out... I mean basically what I do is I talk. That's my job. I do presentations. I do speeches. I do impromptu staff meetings. And it was frustrating at the beginning because I could not talk. And then you know I had to kind of contain my temper sometimes because it was so frustrating.</p>	<p>Feeling fear about inability to regain speech</p> <p>Being unable to talk</p> <p>Becoming frustrated</p> <p>Containing one's temper</p>	<p>Losing one's livelihood</p>	<p><i>Perceiving cancer as an intrusive threat to one's sense of self and daily life</i></p>
<p>P22: So once I was diagnosed I think it was actually a bit worse because I knew I had the cancer. Before, it might not be. It might not happen. You know, it could be nothing. And then when I was diagnosed, it was the stress of telling the kids and not knowing what would happen.</p>	<p>Taking solace in not knowing</p> <p>Feeling stress over disclosing illness</p> <p>Not knowing what's going to happen</p>	<p>Being consumed by uncertainty</p>	
<p>P14: ...even though you're sick, you still have all this paperwork and all these other things that you still need to do, which I find makes it very hard to navigate the [healthcare] system... And I had to take the horrible pills to help you live and in my opinion chemotherapy is poison... and I don't want to go through chemotherapy. I know it's painful, like I really can't bear to go through it but I have to, I have no choice</p>	<p>Being sick but having to take charge</p> <p>Having difficulty navigating healthcare</p> <p>Not wanting chemotherapy</p> <p>Not having a choice</p>	<p>Feeling stuck/trapped from lack of choice</p>	

*Seeking support from health professionals*

Participants were able to gain a sense of confidence from the support they received from their healthcare professionals that they could control and reduce the impact of the illness on their daily life amid some of the challenges and toxicities associated with being treated for cancer. For example, Sharon (67-year-old head/neck & breast cancer survivor) was having a difficult time managing the toxicities of her chemotherapy, noting: "... the first chemo treatment was too strong. They made it too strong. So I was in terrible shape. I was vomiting. I had diarrhea... It [chemotherapy] was terribly hard on the body". However, the support she received from her medical oncologist was monumental in providing her with a sense of control that she was capable of reducing the impact of her treatment:

...Fortunately they reduced the chemo but even then he [her medical oncologist] said there is a risk if we reduce the strength... But I said to myself 'I am never vomiting again with this'. I guess that was the targeted goal I set for myself. I was not going to vomit anymore with this chemotherapy. And I never vomited again!

This quote illustrates that the support Sharon received from her medical oncologist provided her with a sense of control over her ability to mitigate the impact of her treatment on her daily life by meeting her targeted goal of never vomiting again.

Other participants such as Daniel (66-year-old head/neck cancer survivor) and Maria (37-year old breast cancer survivor) received similar support from their oncologists. This support allowed them to feel in control over the impact of their illness. For Daniel, using the recommendations provided by his oncologist gave him control and confidence that he would survive the illness, saying: "Dr. X set my mind at ease and I put my beliefs in him. What he said went. What he said to do, I did. It was hell, but I came out of it at the other end cured. I was fine". Maria gained control by expressing to her oncologist how fearful she was that she was not strong enough to endure her chemotherapy, stating: "By the third chemo I spoke to my

oncologist and I told him I cannot take it anymore... I said that you are going to kill me”. By expressing this fear to her oncologist, she received reassurance that she would survive and was then able to reduce the strength of her chemotherapy and gain more rest between treatment cycles.

He said ‘No, we are not going to kill you’. But I said ‘I cannot take this anymore, I feel like I am going to die’. And he said ‘We are going to reduce the strength’ little bit” and he also asked me to rest. He let me rest and instead of scheduling [more chemotherapy] after two weeks he scheduled it after 3 weeks.

This support gave Maria more control over the impact of her illness.

That said, other participants were not so fortunate with the support they received from healthcare professionals involved in their care. Seeking support did not always provide a sense of control. For example, Jason (51-year-old head/neck cancer survivor) had a difficult time seeking support from his surgical oncologists noting that “...there was a surgeon there that I met with. The whole thing lasted for about less than 3 minutes... It really kind of put me off”. Similarly, Tatianna (35-year-old head/neck cancer survivor) felt her oncologists were not helpful at addressing the late effects from radiation treatment, saying:

... I had a rash on my face and neck and even when I went to the hospital they said it’s been quite a long time since you were done with the radiation so maybe it’s just an allergic reaction. It was exactly where I had my radiation so I think it was not an allergic reaction... they told me to take Benadryl. But it did not help...

While Sara (49-year-old breast cancer survivor) used phrases such as “he was not prepared to listen” to describe her interactions with her medical oncologist. In these types circumstances when support was not provided, participants took control by advocating for their needs to gain support in other ways to mitigate the impact of the illness on their daily life.

*Advocating for one's needs*

Advocating for one's needs occurred when participants felt that they were not receiving immediate or appropriate care from the healthcare system at large or directly from their healthcare team. These circumstances triggered feelings of distress and a sense of helplessness that their illness would worsen and would have a greater impact on their daily life if concerns were not raised and action not immediately taken. For example, when advocating for himself and attempting to access health services, Josh (57-year-old head/neck cancer survivor) stated:

... getting to your point about empowerment, I felt helpless and useless and I was going to myself 'Am I really going to have to wait a month and a half just to get a CAT scan for this thing that I think is growing and that it's like a cancer? I called back and I said this is ridiculous. I can't wait a month and a half for something that is really serious... Sure enough two days later I went in for a scan. Before you know it in less than three weeks I had surgery. So if I didn't call back I would still be waiting to get tested. But in that time I already had surgery...

Josh provided a clear example of a concrete way in which someone with cancer might re-establish control when immediate and appropriate care was not being provided. Ann (66-year-old breast cancer survivor) found herself in a very similar situation and was forced to take matters into her own hands to ensure the appropriate tests were done in a timely manner stating, "... I tried to wait patiently... But I did take matters in my own hands because my next chemo was approaching and I knew that if I didn't get the MRI then they couldn't really see how bad it [her cancer] was...".

Many participants found themselves in these types of situations when timely or effective care was not provided. For example, when Stephanie (26-year-old breast cancer survivor) first noticed a concerning lump on her breast, she had a difficult time getting a biopsy, noting: "...The doctor refused to do a biopsy because he thought it was just normal tissue". After three months

of uncertainty and increasing stress because the lump appeared to get larger, Stephanie took actions into her own hands by going to a different clinician to receive a biopsy.

In these types of cases, as was true for each person, when care was not provided in an effective and timely manner, participants became concerned and prompted them to take control by speaking up and voicing their concerns. When successful, advocating for one's needs was found to be a source of empowerment because it allowed participants to feel in control over the quality of the care they were receiving. Josh provides an example of this type of empowerment. However, in cases when advocating for one's needs was not successful, participants began looking for other ways to establish control and did so by looking elsewhere for additional support.

### *Seeking Additional Support*

Seeking additional support to establish control occurred in three different circumstances. It occurred when participants felt they were not receiving efficient or effective care as shown in the preceding section. Seeking additional support also occurred when participants were curious and wanted to experiment and explore other ways of reducing the impact of their illness on their daily life. For example, Tatianna (35-year-old head/neck cancer survivor) Jackie (46-year-old cancer survivor), Maria (37-year-old breast cancer survivor), and Frank (53 year-old head/neck cancer survivor) sought additional support by exploring complementary and alternative therapies. Frank, for example, explicitly noted how he experimented with various substances to discover what worked best for him, stating: "I experiment. I asked Dr. X about oil from marijuana. I am curious about that... I am even taking vitamins and fish oil. I also juice...". By experimenting, Frank was trying to find alternative ways to reduce the impact of his illness.

In other circumstances, receiving additional support occurred not through experimentation or exploring other types of healthcare, but occurred when participants openly shared their illness experience with other people. Sharon (67-year-old head/neck & breast cancer survivor) noted: “I met wonderful people who were going through treatment... I met a lady... she got cancer 7 times... she must have been 65. She was on her seventh cancer. And she said that she would never give up and I never gave up”. This interaction gave Sharon the strength to keep pushing forward amid the toxicities of her chemotherapy. Billy (65-year-old head/neck cancer survivor) and Maria (37-year-old breast cancer survivor) each spoke about similar moments when they gained additional support by disclosing aspects of their illness to other people. For Billy, this occurred when he confided his experiences to his father in law, which helped me make a treatment related decision to have a laryngectomy, noting:

...my son in law, his father is a haematologist... and I confided in him and he said ‘You know, from what I’ve understood, what I’ve learned, you know, that’s the only option you have’... I said, “I guess we better get it [a laryngectomy] done then!”

In Maria’s case, she was reluctant to cut her hair until she confided and then accepted the support from a friend, noting: “I was reluctant to cut my hair... one of my friends, she is a hair stylist and she said I want to cut it for you. And then she did it. And I felt better that she did it rather than someone else”.

However, in many cases participants found it difficult to disclose aspects of their illness to other people. For reasons that include fear of stigmatization and being treated differently by others, many of those that I interviewed took control over how they spoke about their illness to other people. This type of control was used as a strategy to circumvent changes to one’s sense of self. When keeping aspects of their illness hidden from others, participants had control over how the illness impacted their sense of self.

*Disclosing Aspects of the Illness to Others*

Precaution was taken by many participants when disclosing aspects of their illness to other people including family members, friends, and employers/colleagues because of various fears associated with worrying others and concerns about being treated differently. In this way, participants tried to maintain control over other people's reactions to their illness by deciding whether and how to disclose. Three different strategies were used to maintain this type of control: isolation, selective sharing and concealing symptoms. For example, Jason (51-year-old head/neck cancer survivor) purposely isolated himself from his colleagues as to avoid unwanted reactions or attention from others. He noted:

...It was about 6 or 8 weeks before I really started speaking well and then I went back to work. But even then, when I went to work, I really just stayed in my office because I could not speak properly and then everyone would go "What's wrong?" But, I did not want to make a big deal of it. Nobody at work other than my boss and those that report directly to me knew and I did not want to make a big deal of it so I did not really see a lot of people...

Daniel (66-year-old head/neck cancer survivor) provides an example of how someone can take precaution when disclosing the illness to family and friends by selectively sharing different aspects of his illness to minimize its impact on themselves and on others.

Now at the beginning I didn't tell anybody in my family. Just my wife and my son... I didn't want to tell them because I figured they were going to think I was going to die. And I didn't want them to have that idea. And as soon as Dr. X said that he could cure me 100%, that's when I started to share...

In other situations, participants took control by concealing their symptoms and post-treatment side-effects as a way to protect their pre-illness identity. Lizzy (68-year-old head/neck cancer survivor) began to collect and wear scarves to hide the impact of her cancer surgery:

...they took out a portion of my tongue and a portion of my saliva gland. They basically cut across my throat and now I am left with a 'turkey neck'... and I've learned to deal

with it. Everybody bought me scarfs. I have so many scarfs... it was just so horrible looking... and you couldn't use makeup on it or anything like that...

Tom (66-year-old head/neck cancer survivor) used a similar strategy by purposely growing a beard to hide a noticeable scar on his neck that resulted from his cancer surgery. Control over the impact of side effects was therefore maintained in a variety of creative ways. However, in many circumstances, physical symptoms could not be concealed. Thus, rather than hiding any physical change, other participants learned to incorporate their symptom(s) into daily living as a way to establish control to preserve their sense of identity.

*Incorporating the impact of the illness into daily life*

Incorporating the impact of the illness into daily life as a method of establishing control took many forms depending on the physical issue and the persons' circumstance. Billy (65-year-old head/neck cancer survivor) took a practical approach, understanding that incorporating the physical change was necessary to participate in day-to-day life. As a result of his laryngectomy, Billy had difficulty speaking and relied on an electronic transcribing device to communicate with others. He noted: "I still carry it [the device]... it's pretty handy... where you can write on it and you can rub it off... It's not a whiteboard... You just touch, there's a little button at the top, and whatever you write just disappears". In this way, he was still able to communicate.

For Stephanie (26-year-old breast cancer survivor), Jackie (46-year-old cancer survivor) and Sharon (66-year old cancer survivor) incorporating symptoms into daily living was a decision based not on practicality, but on preserving a particular aspect of their identity. They each chose to have reconstructive surgery after their own respective mastectomies to preserve their identity as women. Stephanie noted: "...I felt kind of silly to go through this horrible pain

just so that I would have breasts. But I know in a year from now I will be happy that I did...I'm really young and I didn't ever want to get rid of my breasts...".

For other participants, incorporating the illness into daily life involved gravitating towards behaviours that brought a sense of normality to everyday life. For example, to feel in control while coping with severe nausea and physical weakness during treatment, Sharon (67-year-old head/neck and breast cancer survivor) noted the following: "It [maintaining a normal routine] was very important to me. And a lot of other people I talked to and survived cancer have said the same thing. For them, keeping part of their normal routine during a very difficult time helps you get through it". Josh (57-year-old head/neck cancer survivor), Ann (66-year-old breast cancer survivor), and Erin (48-year-old breast cancer survivor) also gravitated to normal day-to-day activities to feel more in control during difficult periods. For example, when recovering from his cancer surgery, Josh expressed the following:

... knowing that they [my family] were living their normal lives and just being at home. Being able to walk in the backyard and pet my dog. That kind of stuff rather than sitting in a hospital bed was a big help... just to be around family and being at home...

Ann expressed similar sentiments: "... I was just really mindful and just keeping as much semblance of order for my kids as possible". Erin continued to work during her radiation treatments, but her motivations to keep this semblance of her pre-illness identity were different:

If I have to take time off work, I'm not getting paid for it... the employer could easily say this isn't going to work for us... So, it was a little scary. But we [her employer] were able to work around scheduling of treatment... But you're stressed and you're trying to just go about your daily activities. But I put a brave face on at the office.

Even though Erin's motivations to keep working during her treatments was based on fear of losing her job rather gaining a sense of comfort (as was apparent in Josh's and Ann's experiences), it was a technique she used to maintain control. Thus, in gravitating towards this sense of normality, these participants' pre-illness identities remained intact. Table 4 provides

examples of my initial and focused coding of these same participants' data to illustrate this process of empowerment.

### *Summary*

Empowerment emerged as an outcome when participants were successful at taking control using the 5 noted strategies of seeking support from healthcare professionals, advocating for one's needs, seeking additional support, taking precaution when disclosing aspects of the illness to other people and incorporating aspects of the illness into daily life. Regardless of which strategy was used to take control, discovering various ways to establish control was essential to the empowerment process for many participants. Such processes appeared to connect to a sense of psychological strength: participants were often able to circumvent any significant changes to themselves or their sense of themselves, as well as the ways in which they participated in their daily life.

However, in many cases, tensions arose between being successful and unsuccessful at taking control to circumvent change. For example, when I asked Stephanie (26-year old breast cancer survivor) to elaborate on her thoughts and feelings of having breast reconstructive surgery, she appeared to be conflicted with her choice because her new breasts had a different look and feel, stating:

I had to really figure out if the pain was worth it. I felt kind of silly to go through this horrible pain just so that I would have breasts... It really felt like someone was torturing me... Some people would say, "Oh, you're going to have perfect breasts now" and that's so, like I find that so offensive to me because the pain I went through to get them, it's like almost not worth the pain. And they'll never look nice, like someone who wants a boob job, they're never going to be like that. I've got a huge scar, no nipple any more. They look weird.

Table 4. Being in control over the impact of the illness

Data	Coding	Conceptualization
<p>P9: I think other people saw improvement more than I did at the beginning. Because it goes from not being able to speak at all to kind of making sounds that I could understand but they couldn't... It took 6 or 8 weeks before I really started speaking well. Even in that period after 4 weeks, I went back to work. But even then I went to work part days and really just stayed in my office because I could not speak properly and then everyone would go "What's wrong?" But I did not want to make a big deal of it.</p>	<p>Having other people notice improvements instead of themselves</p> <p>Seeing gradual improvement</p> <p>Isolating oneself</p> <p>Not wanting to make a big deal from going through cancer</p>	<p>Purposely isolating oneself</p>
<p>P22: Telling my kids was horrible. I told my parents first and that was hard. Because as a parent you don't ever want to see your kids sick. And I didn't tell anybody and I wouldn't let my husband tell anybody until I'd absolutely knew what I was dealing with, because I didn't want people to worry.</p>	<p>Having a horrible experience disclosing illness</p> <p>Not wanting to disclose illness</p>	<p>Controlling levels of disclosure</p>
<p>P14: ... each week my chemo got worse and my side effects got worse. The physical changes that my body went through were very hard for me... my tongue went black. My skin would peel. My toe nails came off. And completely no hair... I would wear gloves because I was so self-conscious. I didn't want anybody to see my hands...</p>	<p>Experiencing progressive worsening of side effects</p> <p>Feeling self-conscious over changes to body</p> <p>'Hiding' the changes</p>	<p>Hiding changes to physical body</p> <p><i>Being in control over the impact of the illness as a means to circumvent an eroding and changing self</i></p>

In this quotation, Stephanie continues to contemplate her choice because she was not entirely successful at taking control to circumvent change. She reflects that her new breasts are different and “look weird”. This change prompts her to contemplate her choice to have breast reconstructive surgery and may demonstrate how she felt conflicted about this method of taking control to preserve her pre-illness identity. When these types of conflicts occurred, many participants engaged in the other process of empowerment associated with letting go and accepting and acknowledging that there were aspects of illness that could not be controlled.

#### *4.5.4 'I Can't Control'*

The inability to be in control over the illness occurred when participants struggled between the 5 methods of taking control to preserve one's sense of self and ability to participate in daily life. During this struggle, many participants came to the realization that there were aspects of their illness that could not be controlled or changed. Ironically, this realization was found to be an alternative way participants developed a sense of empowerment. This alternative way of becoming empowered occurred in a two-step dynamic process of: 1) 'Letting go'; and 2) The acknowledgement and acceptance of change. This alternative experience of empowerment illustrates the paradoxical nature of how this phenomenon emerged from a diagnosis of cancer. Empowerment occurred by being successful and unsuccessful of being in control.

#### *Letting go*

Letting go occurred when participants learned what aspects of their illness could not be controlled. This realization prompted participants to relinquish efforts of trying to influence these types of circumstances. Thus, rather than try to establish control to circumvent change,

participants let go of trying to establish control. The ability of letting go was a form of liberation that participants described as empowering. For example, Jackie (46-year-old breast cancer survivor) said:

...there are certain things you don't have control over. You have no control over death unless you commit suicide or somebody shoots at you, or whatever, but I'm saying certain things are not in your control. So I've learned that I'm only going to control what I can, and the other stuff I just have to let it go.

For Jackie, letting go only occurred when she discovered what she could not control. This included her acknowledgement that preventing cancer was beyond her control: "I did everything I thought I could do to not get cancer and I still got it. So I realized you can't control it". This ability to let go provided Jackie with a sense of freedom that she could move forward with her recovery without being weighed down by the burden associated with her illness. She defined this process of letting go as empowering, noting: "...I feel like it's a huge burden that's been lifted. I feel a lot freer that I'm on my journey to recover".

Paul (65-year-old head/neck cancer survivor) articulated a similar process of letting go when he realized how little control he had over his illness. When discussing the consequences of the surgical treatment for his cancer, he noted the following:

... I had no taste. My eye drooped. I could not open or close the eye. And if you could look at me, god I was probably frightening children. My face was pulled over like that. I was really self-conscious about that. So I was thinking that I really don't want to be out in public. I don't want to be here. I don't want to do this. I don't want to do that. I don't want to be at the church. And I was like that for a few weeks for a 2 to 3 weeks. And you know what I thought? I can't let this thing control me. So I said the hell with it. I put on a pair of sun glasses and go. And that's what I did.

Paul's choice of words at the end of this quote emphasises the process of letting go when he made the decision that he could no longer let the illness control him. This decision helped him become less self-conscious about how he may appear to others and provided him with a sense of liberation that even with his physical changes, he was still able to engage in day to day life. This

decision to let go was associated with his emergence sense of empowerment stating:

“empowerment means you are basically in charge... You always have options. It may not be all good options, but there are always options. You are the guy that makes those decisions.”

However, for most participants, letting go was described in less direct ways. For example, when talking about the mindset needed to push through the difficulties associated with cancer, Frank (53-year-old head/neck cancer survivor) refers to the process of letting go by stating the following: “You have to be positive. I cannot stress that enough... If there is a problem, you have to deal with it and then you have to move on...”. Frank’s emphasis on ‘moving on’ was an indirect way of indicating the importance of letting go and not dwelling on issues that are difficult to manage. This importance of letting go was affirmed when I asked Frank to define empowerment:

Empowerment, how do I define it? It’s mind over matter. You have to understand that you have something wrong with you and if you go with what’s wrong and you stay at that level, you are not going to make it. And it can take years and years and years for you to recover...

This quotation illustrates the conflict that can arise by trying to control constant stressors and being unable to let go and move on from them. Betty (55-year-old head/neck cancer survivor) expressed similar sentiments about letting go by emphasising the importance on not dwelling on the negative and being able to focus on what is enjoyable, stating:

...that word [cancer] can be very scary because you automatically think you are going to die. No matter what they tell you, that’s why you think... but you have to deal with the treatments and in the meantime figure out what’s most important to you and then enjoy it...

This process of letting go is associated with Betty’s definition of empowerment: “... strength. You have to find the strength within yourself ... If you don’t find the strength no matter who you

are, you are not going to get anywhere. You are going to go in a circle...”. In other words, without having the strength to let go, one may feel trapped in the illness experience.

In comparison, Tom (66-year-old head/neck cancer survivor) highlights the prominence of letting go but in a different way by stressing the role of “acceptance” in his own process of healing:

... if I fight what’s sitting in front of me, all I’m going to do is create stress for myself... I have a different mindset than you know that acceptance is the key to all my problems. So when I was diagnosed it was sort of like, well, there’s only one person to blame for this cancer and that’s the guy who did all the smoking and the drinking...

This quotation is in reference to Tom’s guilt that he caused his own illness. He understands that dwelling on this guilt will not be helpful, and therefore must let go, acknowledge and accept his reality. Tom’s choice of words illustrates that along with letting go, participants also needed to acknowledge and accept that there were circumstances associated with their illness that could not be controlled.

#### *Acknowledgment and acceptance of change*

Along with letting go, to develop a sense of empowerment participants needed to acknowledge and accept that there were circumstances associated with their illness that could not be controlled. This type of acknowledgment and acceptance helped participants ‘let go’ to develop a sense of liberation from not dwelling on the afflictions associated with their illness. However, for many participants, this type of acknowledgement and acceptance was difficult. For example, at the time that I interviewed Tatianna (35-year-old head/neck cancer survivor), she was struggling with the notion of not having control:

No, I don't feel empowered. I am not a control freak but I always like to plan ahead. That's just the type of person I am. And this situation [cancer] has been very hard because it showed me that I can't control anything. I can make plans but then one day 'boom!' and it's all going to change. And now I am trying to take one day at a time...

Her decision to try to live life one day at a time is not only an illustration of her attempt to let go, but is also an example of how she is trying to accept and acknowledge her new reality of how little control she has over her life. Since she is struggling with this type of acceptance and acknowledgement, she has not yet developed a sense of empowerment.

Gerrard (61-year-old head/neck survivor) and Stephanie (27-year-old breast cancer survivor) also struggled with accepting and acknowledging how there were certain aspects of their illness that could not be controlled. In each of these cases, these circumstances acted as barriers to developing a sense of empowerment. For example, Gerrard has yet to accept and acknowledge how he may never be able to participate in his post-retirement passion of wood working in the same way prior to his diagnosis of head/neck cancer because of the consequences of his cancer surgery. This has proved to be a source of stress for Gerrard, stating "I'd rather be in the shop working", rather than trying to find innovative ways to create a breathing mask that covers his tracheostomy. He has yet to be successful.

In Stephanie's case, she continues to struggle with accepting and acknowledging the implications of a double mastectomy and her decision to have reconstructive [breast] surgery to re-establish her identity as a young woman. Yet, as mentioned earlier, she concedes that her reconstructed breasts are different and that they "look weird", and continues to struggle with her choice to have reconstructive surgery (see quote on p. 117). As a result, she does not yet feel empowered, stating: "No. I don't, I'm not there [empowered] yet. I think I will eventually get there...".

For participants who were successful at acknowledging and accepting of change, they were able to embrace the afflictions of their illness, which allowed them to develop a sense of empowerment. For example, Josh (57-year-old head/neck survivor) is proud by the fact that he survived cancer and enjoys sharing his experiences with other people, noting:

...when I started socializing again...I was exuberant because I went through hell and everything is over now so “look at my feeding tube! Look this is my optimizer!...” My wife would hold me back. “Don’t be so exuberant with sharing your experiences with everybody”. But, I don’t mind talking about it at all or telling people. It’s kind of like I am revitalized. You get a more of an appreciation of life.

It appears that Jason was able to accept and acknowledge the changes he went through as a result of his diagnosis and treatment for cancer resulting in his emergent sense of empowerment articulated here as his sense of revitalization and greater appreciation for life. Billy (65-year-old head/neck cancer survivor), Sara (49-year-old breast cancer survivor) and Frank (53-year-old head/neck survivor) were each able to accept and acknowledge the afflictions associated with their illness, which contributed to their emerging sense of empowerment. When I asked Billy to discuss his emerging sense of empowerment, he noted the following:

... it [cancer] made me more aware... Because all my buddies know, “you never smoked”. I said, “see it can get anybody”. It happens, that’s all... and you can’t sit back on something like this. You’ve just got to recognize what you’ve got... It’s the new normal.

This type of recognition and acknowledgement was associated with Billy’s sense of empowerment. Tables 5 provides examples of my initial and focused coding of these same participants to illustrate this process of empowerment.

Table 5. Relinquishing control

Data	Coding	Conceptualization
<p>P9: ... But because of this [cancer], I'm little less aggressive... you start to think about your own mortality... and I think it's more about realizing that you don't have much control in life. You know it is what it is. You have to deal with what comes... shit happens and you can either give up or you can fight through and learn from your experiences</p> <p>P22: I waited to tell work [about my diagnosis]. I'm a very private person and I like to deal with things on my own... And I was really relieved when I told them. I could just you know, be a bit more myself and let my guard down...</p> <p>P14: ... I've had to change a lot of views and concepts of my life. What I felt was important is no longer important. How I was doing things wasn't good. I now look at things in a different way and really appreciate nature in its purest forms... because there are certain things you do not have control over. You have no control over death unless you commit suicide or somebody shoots at you... but I'm saying certain things are not in your control. That's how I feel. So I've learned to only control what I can, and the other stuff I just have to let it go.</p>	<p>Becoming less aggressive</p> <p>Facing mortality</p> <p>Realizing one does not have control</p> <p>Having a choice</p> <p>Controlling levels of disclosure</p> <p>Letting one's guard down</p> <p>Being oneself</p> <p>Changing one's perspective</p> <p>Appreciating the things one has</p> <p>Realizing there are many things that cannot be controlled</p> <p>Learning to control what one can and letting go of the rest</p> <p>Realizing one has no control but still has a choice</p> <p>Letting your guard down and being yourself</p> <p>Learning to let go of what one can't control</p>	<p><i>Relinquishing control over aspects of the illness deemed irrepressible and incorporating those aspects into daily life and new sense of self</i></p>

*Summary*

Unlike taking control to develop a sense of empowerment, relinquishing control emerged when participants felt capable of accepting, acknowledging and letting go of attempts to control of aspects of their illness that could not be controlled. By letting go and relinquishing control, participants developed a new awareness that was critical to the process of empowerment because it appears to have shifted their worldviews towards new ways of understanding and incorporating their illness into their life. In other words, in letting go, participants appeared to be able to accept the changes caused by illness and were able to move beyond taking control as the only way to adapt to and survive the threats associated with their diagnosis. This was perceived as empowering.

*4.5.5 Empowerment: Personal Growth and a Display of Fortitude and Strength*

Taken together, empowerment emerged as participants moved between successfully being control over the impact of the illness as a way to circumvent change and by letting go and accepting and acknowledging aspects of the illness that could not be controlled. By moving between these two processes, many participants began to gravitate towards newfound meaning that eventually impacted the ways in which they understood and incorporated their illness into daily living. This ultimately led to a sense of personal growth and a display of fortitude and strength that participants defined as being empowering. In some circumstances, this sense of empowerment was associated with shifting values. As one participant noted:

I am a little less aggressive. I look a little bit more into what I'm doing. I have a 750 guys that work in our business. I think the way I speak to them... I talk more about caring for each other and looking after each other. Whereas in the past, it would be more statistics

of the amount of time lost to injury and that we have to do better. I now have a softer approach to things because you start to think about your own mortality when you go through it [cancer].

(Jason, 51-year-old head/neck cancer survivor)

In other words, in facing his own mortality, Jason experienced a change in his own beliefs and values. In addition, Jason also noted the following: “I think having [cancer] made me realize that you don’t have much control in life. Shit happens and how you deal with it is really a measure of your character... You can either give up or you can fight through and learn from your experiences”. He later acknowledged that having cancer benefited his approach to life: “I would not say that everyone should have cancer and to go through it... but I think it was beneficial. For me personally, it changed my perspective on a lot of stuff”. Thus, even though cancer was perceived as a life-threatening disease, the experience allowed Jason to acknowledge certain things in life cannot be controlled. Cancer changed the way he treated others and he became more caring and empathetic, and this provided him with a sense of empowerment.

Erin (48-year-old breast cancer survivor) also experienced a shift in values, noting: “I try not to let things get me worked up that may have bothered me... life is so short. Why am I worrying when there are so many other things that could happen, so I think it kind of changes your perspective...”. This new perspective has allowed Erin to feel empowered: “Has anything been empowering? I always like the adage that what doesn’t kill you makes you stronger. And that’s what I try to live by. I’ve been through adversity, but I’m not going to let it beat me...”.

For other participants, it was not necessarily a shift in a belief but a discovery of something new that resulted in change. Joe (64-year-old head/neck cancer survivor) embeds his sense of empowerment in his discovery of ice cream:

I discovered ice cream. Häagen-Dazs, I put on 30 pounds! It was right at the check-out counter at the grocery store!... I looked at it and I wondered how good that was. I think it

was cherry chocolate chunk. So I grabbed one of those and I got home and about dinner time I'll eat this pint of ice cream. I ate about half of it and I was hooked!

To give this quote context, Joe was experiencing a sense of loss and struggled from physical and emotional withdrawal by being forced to quit smoking as a result of his diagnosis of head/neck cancer. Not only does he embed his experience of empowerment within his ability to quit smoking, his new-found love for ice cream replaced his need to smoke. Joe's example of empowerment is an illustration of the paradoxical nature of the process. To take control, Joe fights his urge to smoke by substituting this addiction with another behaviour as a way to circumvent change. Simultaneously, this substitution is a reflection of his 'letting go' of the need to smoke, which allowed him to discover something new.

For other participants, empowerment did not emerge from a specific discovery but a newfound confidence resulted from experiencing and pushing through the hardships associated with having cancer. As a 49-year-old breast cancer survivor and director of human resources for a large company at the time of her diagnosis, Sara was apprehensive and refrained from disclosing her illness to her employees out of fear she would appear weak and worry others. When she decided to forgo this type of control, she stated the following: "...I was really relieved that I told them and I could just you know, be a bit more myself and let down my guard". She later explained that these types of experiences gave her an empowered sense of self: "...These experiences have empowered me. It's made me much more confident in who I am...". Thus, Sara's experience reflects a process of moving between taking control (refraining from disclosing her illness) and then 'letting go' (disclosing her illness), which brought her a newfound confidence in her sense of self. In addition, Sara gained an appreciation for going through the illness:

Sometimes you get caught up in life and sometimes you just don't take the time to reflect. So I think [cancer] forced me to be a better person. I have more patience and more time to give to my family and I am thankful of that... All the bad stuff has given me some really good things... It was a bad experience. It was a year of my life but, I have really great things to take away from it... so it [cancer] has changed me for sure. I'm glad I have cancer... And I feel very proud of you know, the fight...

Thus, regardless of how participants defined what was meaningful, as they moved between taking and letting go of control they began to re-interpret the meaning of their illness. They no longer viewed cancer as simply a threat but as a beneficial experience associated with personal growth and an opportunity to display fortitude associated with survival. This reinterpretation did not occur instantaneously, but as a cumulative process of opening up to new ways of understanding and incorporating the illness into daily living. This was the epitome of the empowerment process.

#### ***4.6 Summary***

Empowerment consists of two dynamic and paradoxical processes associated with taking and relinquishing control over and re-interpreting the threats associated with a diagnosis of cancer and its treatments. Defined by participants as a testament of one's inner strength and ability to push through and survive the varying challenges associated with having cancer, empowerment became more than simply trying to establish and maintain control; it also included the ability to accept and adapt to circumstances where control over the illness was seen as unattainable. This realization allowed some participants to think differently about the challenges associated with their diagnosis; as they learned how to incorporate their illness into daily living, they saw cancer not simply as a threat but as an experience associated with personal growth. This was the process of empowerment.

## **Chapter 5 Discussion**

### ***5.1 Introduction***

Empowerment is a phenomenon most commonly associated with taking control. As a concept emerging during the civil rights movement of the 1960s and 1970s, empowerment has become a buzzword that describes the resiliency and fortitude needed to re-establish authority and autonomy when people are exploited, victimized, or feel helpless. In the case of a life-threatening illness such as cancer, the use of the word empowerment connotes meaning associated with taking control and fighting for survival, in addition to being proactive and managing one's own care. While my findings reflect this view of empowerment, it also introduces a second paradoxical process—the act of relinquishing control. When these findings are compared and contrasted with traditional ways of understanding empowerment, a number of insights can be drawn and recommendations made that speak to the applicability of this theory of empowerment to cancer rehabilitation.

### ***5.2 Empowerment in Relation to Cancer Survivorship Discourse***

First and foremost, the idea of an empowered patient is strongly entrenched in the dominant cancer survivorship discourse. Scholars studying this discourse illustrate that a narrative describing a specific archetype of how to survive cancer is embedded within popular representations of the illness (see Thomas-MacLean, 2005; Kleinmann, 1988; Frank, 1995). That is, someone can survive by demonstrating a sense of strength and resiliency from enduring the physical and psychosocial trauma associated with the illness over and above developing the aptitude to manage one's own care (Smith et al., 2016; Conrad & Barker, 2010; Thorne &

Murray, 2000). Thus, surviving cancer is understood to be an accomplishment reflective of a person's ability to take control and fight for survival. This grounded theory of empowerment reflects the dominance of this narrative.

However, also emerging from the theory is a conflicting narrative associating empowerment with a process of accepting situations when control is perceived as unattainable. This form of empowerment is rarely discussed in the literature (see Bell, 2014; Ristovski-Slijepcevic & Bell, 2014; Khan, Rose, & Evans, 2012b; Kaiser, 2008; Sinding & Gray, 2005; Fox, Ward, & O'Rourke, 2005) and is less prominent in the dominant discourse. In fact, this way of understanding empowerment contradicts the popular archetype that describes how people should address the difficulties and threats associated with having cancer. Above all else, the discourse suggests that someone diagnosed with cancer must continue to fight for control in order to survive the illness. Those who do not continue the fight, as Steinberg (2015) notes, are perceived as bad patients who are passive, are psychologically weak, and have lost their will to live.

Yet, for my participants, de-emphasizing efforts associated with establishing control was not associated with any form of disengagement or lack of resiliency but, rather, spoke to an alternative way people became empowered from their illness—a process of letting go and accepting circumstances when establishing control was perceived as impractical. Therefore, the grounded theory that emerged captures a neglected aspect of the illness experience. That is, how do individuals diagnosed with cancer become empowered when they determine that it is no longer practical or feasible to continue to fight for control? Simply put, they become empowered by letting go of the 'fight' and re-focusing their attention towards incorporating those aspects deemed irrepressible into experiences of empowerment.

Unequivocally, this type of adaption is not novel, and is often reflected in qualitative studies that stress what many cancer survivors describe as finding the new normal (see Sandsund, Pattison, Doyle, & Shaw, 2013). Yet, the manner of acclimatizing to this new reality is rarely emphasized as a dynamic process. In addition, this process of taking control and ‘letting go’ contradicts the archetype that describes how people should react to the difficulties and threats associated with having cancer. Nevertheless, the grounded theory that emerged illustrates that empowerment is more complex than simply [re]establishing control. Becoming empowered also includes conceding to the notion that taking control may not always be feasible or practical, which undeniably contradicts the ‘survivorship’ mentality that forms the basis of how we treat, manage, and rehabilitate those diagnosed and living with the consequences of cancer.

### ***5.3 Empowerment as a Dynamic Process***

Most studies approach empowerment as equivalent to control, with fewer inquiries exploring the dynamic ways this phenomenon can emerge. For example, in their phenomenological inquiry of empowerment from the perspective of 12 haematology cancer patients, Bulsara et al. (2004) illustrate that accepting periods of no control is an integral characteristic of the process of empowerment and an antecedent to re-establishing control. However, acceptance of limited control was understood as a temporary period of disempowerment rather than a permanent fixture of a new and empowering reality that participants of my study emphasized. Similarly, in her concept analysis of empowerment in cancer survivorship, Jerofke (2013) postulates that empowerment is a dynamic process of “navigating periods of being ‘well’ and periods of being ‘ill’ associated with alternating periods of feeling empowered [in control] and disempowered [not in control]” (p. 160). Here, a lack of

control is understood as a disempowering characteristic. For my participants, accepting periods of no control was associated with developing a new and empowered sense of self, rather than disempowerment.

What may be emerging from my results are some of the long-term implications of constant fluctuations between feeling in and out of control. Cancer is an illness that can have a life-long impact, which suggests constant fluctuations between periods of feeling well (in control) and feeling sick (not in control). What are the long-term implications of these types of fluctuations? My results suggest that a possible long-term implication is eventually surrendering to the idea of ever being in control over certain aspects of the illness, which for my participants was a form of liberation. However, this view of empowerment is counter-intuitive to traditional ways this phenomenon is understood.

Empowerment is a multi-level construct that begins at the individual level (Schulz et al., 1995). At the individual level, empowerment is commonly approached by developing a person's knowledge, competency, and sense of self-efficacy over and above building the determination to address any threat or sense of helplessness. Iterations of Bandura's theory of self-efficacy and Deci & Ryan's theory of self-determination form the basis of this understanding (see Cattaneo & Chapman, 2010; Aujoulat et al., 2007). Yet, these theories do not seem to consider how empowerment might also occur in situations perceived as beyond the control of the individual.

Participants in my study noted several hardships that were beyond their control. Physical impairments associated with eating and speaking as well as facial changes were commonly reported by those participants with head/neck cancer as aspects of their new reality that could not be changed. Those with breast cancer noted other types of difficulties related to the physical and psychosocial trauma associated with more complex cancer treatments; specifically, brain fog,

chronic pain and fatigue, premature menopause, lymphedema, and the distress associated with full or partial mastectomies were common struggles. Surprisingly, even with these differences between head/neck cancer and cancer of the breast, similar adapting strategies were used and reflected the dynamic process of empowerment of moving between establishing and relinquishing control as participants learned what aspects of their illness were manageable. This process helped them adjust to their new reality.

Yet, some differences between the two sub-samples were also evident. For example, participants with breast cancer focused much less on the physical impacts of their illness and spoke in much more detail about the psychological and social challenges associated with maintaining specific identities and connected to traditionally female roles. The ability of participants to be a mother, wife, or grandmother were often discussed, but paid work was also significant. My interview with Sara (49-year-old breast cancer survivor) is an example. Sara spoke in great detail about how her roles as a mother and as a top executive for a large company were impacted by the distress associated with her diagnosis. It was only when I asked her specific questions about the physical impact of the diagnosis that she mentioned migraines and her concerns with fertility, both believed to be consequences of taking tamoxifen.

Interviews with participants diagnosed with head/neck cancer focused far less on the psychological impact related to maintaining certain social roles and more on the physical impact of the illness related to their ability to participate in activities of daily living such as eating, speaking, socializing, and engaging in leisure. No gender differences were noted between how women and men with head/neck cancer spoke about their illness, with the exception of Tatianna (35-year-old head/neck cancer survivor). She spoke of issues in ways similar to the women with breast cancer, focusing on her inability to be a mother to her two young children because of the

psychological trauma associated with her illness. This exception could be due to her life stage, because all of other women diagnosed with head/neck cancer were much older.

While these differences in experiences may be reflective of the ways in which these cancers impact certain parts of the body, I did not detect any differences when it came to the experience of empowerment. When any physical and psychosocial challenge was encountered, each person engaged in the dynamic paradoxical process of taking and ‘letting go’ of control regardless of whether they were diagnosed with breast cancer or cancer of the head/neck. In addition, this dynamic process of empowerment was not limited to managing physical or psychosocial consequences related to a diagnosis, but also included managing challenges associated with accessing timely healthcare. For example, many participants spoke about their frustrations with the lack of responsiveness of the healthcare system, noting several circumstances when their clinicians disregarded their concerns, referrals were not made, and treatments or medication were not accessible. Even though many participants tried to establish control over these circumstances, access to healthcare was seen as outside of their control; any difficulties and problems encountered were deemed inherent to a strained and resource-deprived universal [Canadian] healthcare system. ‘Being lucky’, ‘being at the right place at the right time’, and ‘being protected by a higher power’ were common themes used to explain when access to care was stress-free. Thus, although participants tried to take control in these circumstances, many perceived access to better care as beyond their influence. Eventually, they took solace in the care they had already received and advocated for, and this action of ‘letting go’ contributed to their sense of empowerment.

Thus, my results show that empowerment can occur in situations when a person does not feel in control. This view contradicts those theories and models of empowerment that suggest

increasing knowledge, competency, and sense of self-efficacy; increasing access to resources; and fostering better relationships between people are the only ways to empower those who feel exploited, victimized, or ill (see Bravo et al. 2015; Cattaneo & Chapman, 2010). For example, the model of empowerment developed by Cattaneo & Chapman (2010) (see Figure 1) emphasizes a dynamic iterative process of defining and re-defining 'power oriented' goals based on changes to a person's knowledge, competency, and sense of self-efficacy. My model of empowerment illustrates that empowerment can occur in the absence of increased knowledge, competency, and sense of self-efficacy when a person is willing to accept that they may not be able to develop the skills needed to reach an intended goal. In these situations, they re-direct their attention to other meaningful behaviours.

When compared to Bravo et al.'s (2015) model of empowerment (see Figure 2), my findings illustrate the importance of understanding empowerment as a paradoxical dynamic process that begins with perceiving and experiencing a threat. Bravo's model does not consider this dynamism by situating empowerment as a process that emerges from enhancing and respecting patient autonomy and increasing their knowledge and competencies. My model shows that empowerment can emerge paradoxically from disrespecting patient autonomy. This disrespect would initiate the paradoxical process of moving between taking and letting go of control to learn how to re-establish that autonomy or accept that, in some specific circumstances, autonomy might not be possible. In other words, empowerment would emerge by taking control and advocating for better care and by 'letting go' and accepting when care is simply not accessible. This dual nature of empowerment reflects a paradoxical process that is not clearly articulated in Bravo et al.'s model.

#### ***5.4 Applying my Grounded Theory to the Field of Cancer Rehabilitation***

In cancer rehabilitation, empowerment is most readily linked with re-establishing a sense of control and autonomy that is lost when individuals encounter any form of participatory or functional limitation associated with being diagnosed with and treated for cancer. A diagnosis of cancer can be disabling in many ways. Most notably, cancer treatments are toxic and harmful to the physical body and threaten a person's ability to care for themselves and engage in their life in meaningful ways. These side effects can be short term, such as temporary hair and weight loss, or long term, such as cancer-related fatigue, chronic pain, or loss of physical function. Furthermore, the psychological stress associated with diagnosis can also be debilitating. Distress is common across the cancer trajectory, beginning at diagnosis and extending to the post-treatment stages. Concerns related to managing treatment side effects, the inability to access timely healthcare, or the experience of discrimination or stigmatization from having cancer can trigger various levels of distress and make people feel they have very little autonomy and control over their health and life (Howell & Olsen, 2011). Empowerment is a concept applied in cancer rehabilitation to address these challenges by helping people regain a sense of control and autonomy so they can [re]engage in their life in meaningful ways during and after cancer treatment. However, as shown in my literature review, the process through which people take control to manage the impact of being diagnosed with and treated for cancer has not been well documented (see Howell et al., 2017; McCorkle et al., 2011). Thus, this grounded theory of empowerment is one of the first models to map this process. Emerging from my results are two different strategies that participants used to manage their illness, associated with a person's ability to successfully take and let go of control. Not only do these two methods of disease

management conflict, they support as well as illustrate the gaps in current rehabilitation practice in cancer care.

To date, cancer rehabilitation has predominantly focused on symptom control as the primary means of addressing concerns related to functional autonomy and participation in daily living (see Hunter et al., 2017a; Hunter et al., 2017b; Salakari et al., 2015; Egan et al., 2013). For example, Egan et al. (2013), in their systematic review of current cancer rehabilitation practice, illustrate that the most common outcome measurements to address functional concerns are based on comparing symptom reduction with increases to participation in daily living. These interventions utilize different behavioural change approaches to provide the knowledge, resources, skills, and confidence necessary to allow each person to maintain a sense of normality in their life amid the difficulties they may experience from their diagnosis with and treatments for cancer. However, according to the grounded theory that emerged, empowerment should be an outcome from these types of rehabilitation interventions. When these interventions are successful, cancer survivors should feel competent that they can circumvent change by having the ability to control the impact of their illness. This control should generate a sense of empowerment. However, evidence for these types of rehabilitation interventions remains limited, with the strongest support instead found for pharmacological treatments and physical therapy/exercise. There is far less corroboration for interventions that use psychotherapy/counselling and psycho-educational modalities (see Hunter et al., 2017a; Hunter et al., 2017b; Salakari et al., 2015; Egan et al., 2013). Thus, cancer rehabilitation using symptom control as the primary means of addressing functional concerns remains limited and therefore might not be empowering for the individual. What about other approaches to rehabilitation?

Rehabilitation is an area of healthcare that utilizes various methods to address functional concerns. Symptom control is one of many possible strategies. For example, the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO) illustrates that changing the physical environment or altering the activity to incorporate the health condition are other ways to address participation concerns. Yet, these approaches appear to be less utilized in cancer rehabilitation (see Cheville et al., 2017, p. 8; Gilchrist et al., 2009, p. 209). For example, neither the Prospective Surveillance model (Stout et al., 2012) nor the Stained Glass Cancer Rehabilitation Framework (Pearson & Twigg, 2013)—the only identified rehabilitation models designed to address functional concerns associated with the diagnosis and treatment of cancer (see Chapter 2, p. 53-56)—appear to incorporate the full scope of what rehabilitation involves. The Prospective Surveillance model appears to rely on ongoing surveillance and symptom monitoring as the primary mode of rehabilitation while the Stained Glass Cancer Rehabilitation Framework uses Maslow’s hierarchy of needs as the theoretical underpinning to address functional concerns. These examples illustrate the limited views associated with what rehabilitation involves.

Reasons for the exclusion of other approaches to cancer rehabilitation are well documented (see Alfano et al., 2012; Cheville et al., 2011; Franklin, 2007), and include a lack of input from rehabilitation scientists or clinicians such as occupational therapists, physiotherapists, or speech–language pathologists in developing evidence-based guidelines to address concerns with participating in daily life. As Egan et al. (2013) note, “[t]hese issues [pain, mobility and functional problems] were first noted and studied by specialists in psychosocial oncology and supportive care, areas which have not traditionally had the benefit of substantial access to rehabilitation services” (p. 12). As a result, there remains little distinction between what cancer

rehabilitation involves compared to other areas of cancer survivorship care, such as palliative and supportive care. Silver et al. (2015) state in their article *Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services* that:

Although palliative care and rehabilitation can play important roles in improving QOL and survivorship, both services are often misunderstood by health professionals and the public as well. Confusion about the scope and focus of these subspecialties may exist even within oncology care. For example, rehabilitation is often confused with exercise or fitness programs, and many rehabilitation research studies and clinical interventions are described as “exercise” only and do not address the range of impairments that patients and survivors encounter.

(p. 3636)

In other words, without a clear distinction between the different areas of cancer survivorship care, there is a lack of due process in detecting functional concerns associated with cancer. This same argument is corroborated by McEwen et al. (2016) in their article titled: *“I didn’t actually know there was such a thing as rehab”*: Survivor, family, and clinician perceptions of rehabilitation following treatment for head and neck cancer. Without proper detection, it is difficult to provide any type of cancer rehabilitation. In circumstances when proper rehabilitation is not provided, cancer survivors may naturally gravitate towards accepting and acknowledging that the healthcare system is unable to provide them with the care and support they need. In doing so, they may still experience empowerment even when care is not being provided.

My findings corroborate this possibility. Participants in my study did not only rely on establishing control to remain or regain function; they also engaged in a process of adapting to and incorporating aspects of their illness deemed irrepressible into daily life, thereby discovering new ways of participating in various activities. Participants were able to engage in this process with or without proper cancer rehabilitation. None the less, this process of adapting and incorporating does not appear to be explicitly utilized when addressing functional concerns. This

lack of consideration speaks to the various ways my findings can be incorporated into the field of cancer rehabilitation.

First, my findings illustrate that, in addition to teaching survivors how to minimize the burden associated with their illness, cancer rehabilitation could involve strategies that explore processes of adaptation to learn how cancer survivors incorporate symptoms into daily living. , The grounded theory from this study could be used as a framework to design interventions that incorporate strategies associated with adaptation while also continuing to refine current evidence-based practices that use symptom control as the primary means of delivering cancer rehabilitation. This incorporation could include developing patient education strategies that teach skills associated with self-management.

Similar to other chronic illnesses, the effects of cancer and its related costs are unsustainable in the current healthcare system (Phillips & Currow, 2010). Self-management is a possible strategy to address such concerns. Yet, in a recent systematic review, Howell et al. (2017) conclude that a core set of participatory principles for building successful self-management interventions have yet to be identified. This grounded theory could help to identify and then incorporate core principles in cancer rehabilitation interventions emphasizing self-management. For example, based on Howell et al.'s (2017) findings, principles are suggested for three different types of self-management support and educational programming: 1) adjustment-focused programs; 2) problem-focused programs; and 3) a mix of both. This grounded theory supports and reinforces the importance of using these different approaches in teaching self-management skills. It also provides a framework to explore how exactly cancer survivors adjust to their specific circumstances that can then be used to design specific self-management interventions.

Lastly, this grounded theory of empowerment provides a more comprehensive understanding of a phenomenon that is continually used in cancer rehabilitation and more broadly within cancer survivorship care. Empowerment is a term often used interchangeably with other concepts such as patient-engagement and patient activation. Without exploring the differences between these concepts, interventions that use these concepts might suffer from methodological limitations. My work illustrates some possible differences between empowerment and these concepts. For example, when compared to more traditional ways of defining empowerment, such as aligning the concept with enhancing control (see Gibson, 1991, p. 359), my theory illustrates that empowerment is less about control and is more aligned with the ability to either circumvent change or having the power to create and embrace change. This understanding is more holistic and associated with definitions that articulate empowerment as a process of change and adaptation (see Aujoulat et al., 2007, p.18). This definition is distinct from concepts such as patient-activation and patient-engagement, which have a strong focus on enhancing control. My findings suggest that empowerment is a process that goes above and beyond enhancing control. Empowerment includes a process of relinquishment and could, therefore, be seen as a distinct and unique concept.

### ***5.5 Recommendations***

Based on my findings, I make a number of recommendations to possibly improve the rehabilitation of cancer survivors. First, my theory illustrates that people react to cancer in different ways that might not always reflect the dominant discourse surrounding cancer survivorship. People with cancer might feel stigmatized when they do not react to cancer as a debilitating illness that can only be survived by being in control. My theory provides evidence

that establishing control is not the only pathway towards rehabilitation. In addition, some caution is required with respect to the use of language. Concepts such as ‘empowerment’ are used liberally without incorporating survivors’ perspectives. This type of recommendation has been made by other scholars (see Ristovski-Slijepcevic & Bell, 2014), based on similar arguments around the using labels such as ‘cancer survivor’ to describe people who are diagnosed and live with the illness. The language we use to describe the illness has repercussions for self-management. Lastly, more research is needed to explore how cancer can be a disabling illness and the implications for rehabilitation. Often, those who finish treatment are left on their own to cope with the long-term consequences. Given that more people are surviving cancer, it is imperative that we include rehabilitation scientists in program development and intervention design.

### ***5.6 Limitations***

This study has some notable limitations. With the exception of one participant, this study explored the experiences and perceptions of empowerment with people who at the time of their interview were cancer free. Thus, my model of empowerment reflects the beliefs and attitudes associated to those who have ‘survived’ cancer. The processes of empowerment could very well be different in a palliative population and for those who are at end of life. In addition, according to the demographic data that I collected, more than half of the people I interviewed were highly educated (16/22 had a college/university education or above) earning an annual net income of no less than \$61,000 per year (12/22). Thus, the model of empowerment may be also limited to a highly educated and affluent population. Second, this grounded theory of empowerment is a reflection of the co-construction of meaning between myself as the researcher and the

participants of this study. Therefore, these findings are limited to the people involved and the context in which this study took place. This limitation is a reflection of the theoretical lens (social constructivism) used to explore this phenomenon. Within this lens, there is possibility that my understanding of the data shaped the findings of this study and that the experiences of my research participants are not accurately represented. However, the rigorous procedures I used when collecting and analysing my data should ensure that my findings accurately represent the experiences of those that I interviewed. Therefore, the limitations associated with using a social constructivist lens may not apply.

### ***5.7 Future Research***

Further research is needed to explore the processes of empowerment in other cancer populations, including those who are palliative or at end of life. Additional research is also needed to determine the best pathways for interventions emphasizing patient empowerment. For example, theories associated with behavioural change, such as self-determination theory and theories of social learning that use self-efficacy as a core construct, are used to develop interventions that teach cancer survivors the most effective ways to reduce the burden associated with cancer (see Foster et al., 2015). How might these same theories be applied to assist in the processes of empowerment? In addition, are there any other theories that can assist in understanding and facilitating the processes? For example, theories such as transformative learning (Dubouloz et al., 2010) that outline processes associated with incorporating a disability into daily living as well as the transactional model of stress and coping (see Park & Folkman, 1997) that illustrates how people make sense and adapt to stressful events might offer some potential for cancer rehabilitation and could be explored.

### *5.8 Concluding Remarks and Contributions*

The purpose of this doctoral study was to explore empowerment as a phenomenon people experience throughout the cancer trajectory. Using the grounded theory method and a social constructivist lens, the processes by which people became empowered were illuminated. Emerging from my results are two dynamic strategies that participants used to manage their illness to develop a sense of empowerment. One method was associated with being in control and having the ability to circumvent changes to physical function, daily routines, and social roles amid disability. Other processes were associated with relinquishing control; this involved incorporating the afflictions caused by the illness into daily living, and thereby discovering new and meaningful ways to participate regardless of disability. Both strategies were defined as being empowering. As such, my findings illustrate the importance of designing interventions that support cancer survivors to live with, adapt to, and incorporate disability into daily living. Finally, my work contributes to the field of cancer rehabilitation by providing a theoretical framework to explore additional strategies to rehabilitate those with cancer.

## Appendix A



### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**OFFICIAL TITLE:** Empowerment from the Perspective of Cancer Survivors: A Grounded Theory Study

**LAY TITLE:** Exploring the meanings and experiences of re-establishing control: Managing the physical, psychological and social consequences of cancer

**LEAD RESEARCHER:** Jonathan Avery, PhD Candidate, School of Rehabilitation Sciences, University of Ottawa

**PRINCIPAL INVESTIGATOR:** Doris Howell, RN, PhD, RBC Chair, Oncology Nursing Research and Education, University Health Network; Scientist, Psychosocial Oncology, Ontario Cancer Institute; and Associate Professor, Lawrence S. Bloomberg Faculty of Nursing

**CO-INVESTIGATOR:** Roanne Thomas, PhD, Associate Professor, School of Rehabilitation Sciences, University of Ottawa

**CONTACT INFORMATION:** You may contact the lead researcher of the study, **Jonathan Avery**, via email at <mailto:jonathan.avery@uhnresearch.ca> or by telephone at (416) 340-4800 ext. 5058. [You may also contact the Principal Investigator of the study, Doris Howell](#), via email at [doris.howell@uhn.ca](mailto:doris.howell@uhn.ca) or by phone at (416) 946-4501 ext. 3419.

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the investigator(s) listed above to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is completely voluntary.

**WHY IS THIS STUDY BEING DONE?**

Although every person's cancer experience is different, finishing cancer treatment can pose challenges for many people. People may be confronted with a combination of physical, social, emotional and practical concerns and can make people feel that they do not have control over their life. As part of a PhD thesis, the researcher is interested in exploring the experiences and perceptions of control and the ways in which people try to re-establish control to manage the challenges they face from their cancer diagnosis and treatments. For example, how do people try to re-establish control? Is re-establishing control important? How does this help them cope and manage the physical, social, emotional and practical concerns they may face?

**WHO WILL TAKE PART IN THE STUDY?**

Approximately 15-25 head and neck and breast cancer patients who have completed treatment **in the past 3 months - 3 years** will be invited to participate in this study. You have been identified by your health care provider(s) as being eligible to participate. We hope that you will consider sharing your experiences about your cancer with us.

**WHAT IS INVOLVED IN THE STUDY?**

This is a qualitative study. Qualitative research is concerned with people's perspectives on particular phenomena.

If you choose to participate in this study, you will be required to complete a brief questionnaire to provide basic information about yourself (age, diagnosis, marital status, income, etc.) and participate in an approximately 60-90 minute, one-on-one in person interview with the researcher. The interview will consist of questions about your cancer experience, what it was like to be diagnosed, to go through treatment and what it is like now as someone who has completed treatment. This interview will be audio recorded, with your consent.

The interview will take place in a private room at the Princess Margaret Cancer Centre or in a private room located in the ELLICSR: Health, Wellness & Cancer Survivorship Centre located in the Toronto General Hospital. If these locations are not convenient for you, then another more suitable location or a telephone interview can be arranged.

**HOW LONG WILL YOU BE IN THE STUDY?**

You will be considered enrolled in the study for the entire duration of the study; however your active participation in the study will consist of the completion of the demographic form and an approximate 60-90 minute, one-on-one interview. Participation may also include a follow-up interview if a need arises to elaborate more on your experiences. You may receive a follow-up phone call or email to establish a date and time for a follow-up interview. This interview may take place in person or over the phone, depending on your preference.

**WHAT ARE THE RISKS OF THE STUDY?**

There are no known risks to participating in this study. Talking about your cancer experience may be uncomfortable or upsetting. Should this happen, the interview may be paused, stopped and resumed at any time. You may also request a referral to the Psychosocial Oncology and Palliative Care Program at the Princess Margaret Cancer Centre for counseling, if desired.

**ARE THERE BENEFITS TO TAKING PART IN THE STUDY?**

There are no known benefits to participating in this study. Some people might find it beneficial when they discuss and share their experiences in a confidential and safe environment.

**WHAT ARE YOUR RIGHTS AS A STUDY PARTICIPANT?**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may choose to skip any question you do not wish to answer by saying “pass” during the one on one interview. You may leave the study at any time without affecting your follow-up or future treatment and care at the hospital. Deciding not to take part or deciding to leave the study later on will not result in any penalties of any kind.

**WHAT ABOUT CONFIDENTIALITY?**

If you agree to participate in this study, the researcher will collect demographic and contact information (information they need to identify you) which includes such things as your name, email address, phone number, age, and cancer diagnosis from your medical record. Your name, email address and phone number are being collected in the event the researcher would like to set up a follow-up interview. Your contact information will be kept separate from all other information about you to protect your confidentiality and anonymity.

The information that is collected for the study will be kept in a locked and secured confidential location by the research team for 10 years and then destroyed according to UHN Policy. Only the study team and the UHN Research Ethics Board will be allowed to look at your record at the study site. All information collected during this study, including your demographic information and the recorded and transcribed interviews, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study. If you decide to leave the study, the information about you that was collected before you left will still be used. No new information will be collected without your permission.

The individuals (e.g. doctors, nurses, etc.) directly involved in your care will not see your responses to the interview questions nor have access to the audio recordings. Your health care will not be affected by your participation in this study.

**WHAT ARE THE COSTS?**

There are no financial costs associated with taking part in this study, other than the cost of transportation and/or parking to attend the interview. You will be reimbursed up to \$20 for such costs. You will not be paid for taking part in this study.

**COMPENSATION**

If you become ill, injured, or harmed as a result of taking part in this study, you will receive care. The reasonable costs of such care will be covered for any injury, illness, or harm that is directly a result of being in this study. In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

**WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?**

If you have questions about taking part in this study or if you suffer a research-related injury you can talk to your health care providers. Or, you can contact the study investigators Jonathan Avery at (416) 340-4800 ext. 5058 and/or Dr. Doris Howell (416-946-4501 ext. 3419) at any time.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

**CONFLICT OF INTEREST**

The researchers have an interest in completing this study. Their interests should not influence your decision to participate.

Exploring the meanings and experiences of re-establishing control: Managing the physical, psychological and social consequences of cancer

### Consent

I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study. I may withdraw at any time without affecting my medical care. I will receive a signed copy of this consent form. I voluntarily consent to participate in this study.

\_\_\_\_\_  
*Participant's Name (Please Print)*

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Date*

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

\_\_\_\_\_  
*Name of Person  
Obtaining Consent*

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Date*

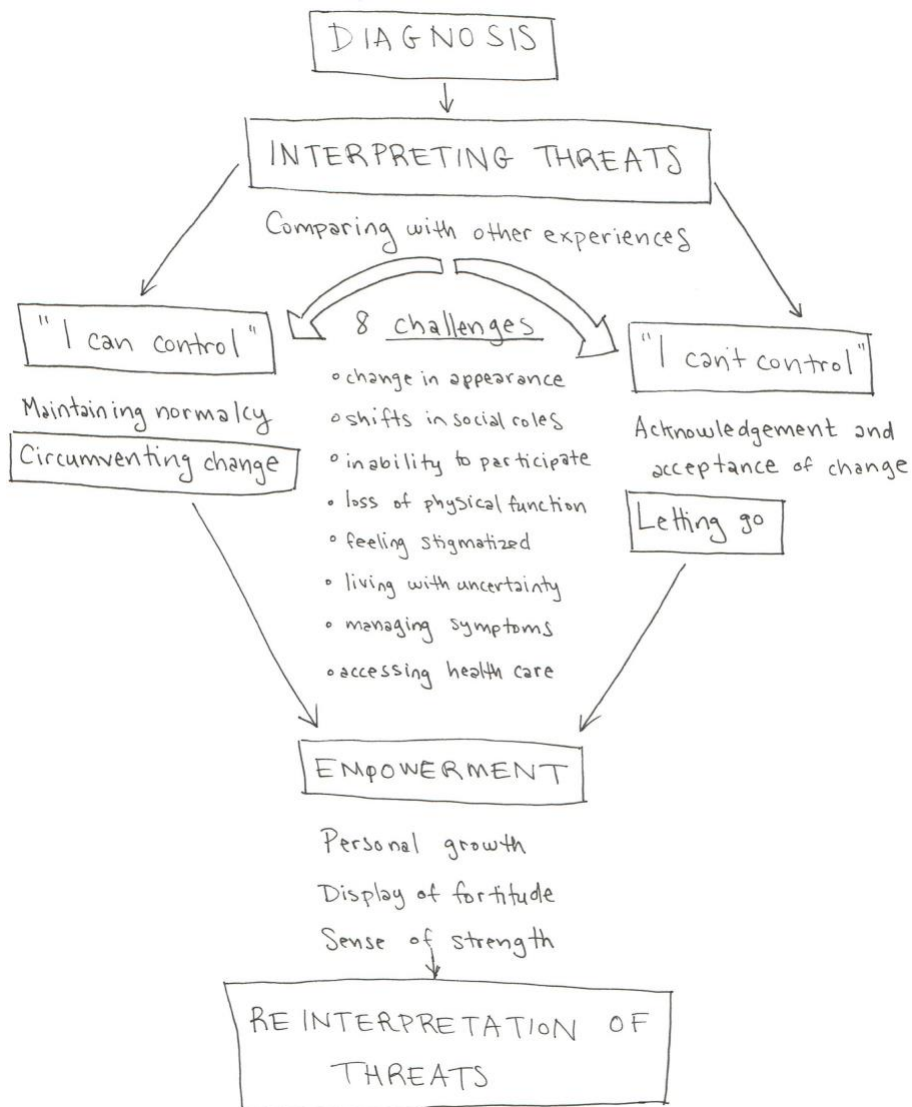
## Appendix B

### Interview Guide

Topic	Question	Probes
Life before the diagnosis	“What was your life like before you were diagnosed with head and neck/breast cancer?”	<ul style="list-style-type: none"> <li>• What did you do for work/leisure activities?</li> <li>• What were your main roles and relationships with your family/friends/community?</li> <li>• What was most important to you prior to your cancer diagnosis?</li> </ul>
The experience of being diagnosed and treated for cancer	“Can you tell me about your experience being diagnosed and treated for head and neck/breast cancer?”	<ul style="list-style-type: none"> <li>• What were some of the challenges?</li> <li>• How did you manage through these challenges?</li> <li>• What role did your family/friends/clinicians have in the management of these challenges?</li> <li>• How did your roles and responsibilities in your life change as you went through your treatment?</li> <li>• How did you try to manage these concerns? Can you expand on some of the strategies?</li> </ul>
The experience of transitioning from treatment to post-treatment life	“What was the process like when you finished your treatment?”	<ul style="list-style-type: none"> <li>• What were or are some of the physical/psychological/social concerns you are/have faced since you have finished your treatments?</li> <li>• How did the treatment phase affect your relationships with your family/friends/co-workers? Can you speak more about this?</li> <li>• Can you talk about some of the support you received from family/friends/clinicians around the management of these concerns?</li> </ul>
Empowerment	“Based on the experiences and challenges that you’ve expressed, what is your understanding of the word empowerment?”	<ul style="list-style-type: none"> <li>• How important is this idea of control over your health and care?</li> <li>• What did you try to do to establish this level of control?</li> <li>• How does this level of control help you manage _____ (example of symptom)?</li> <li>• Can you walk me through the process?</li> </ul>

## Appendix C

### Preliminary sketch of the grounded theory



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