

EXPLORING EQUITABLY HIGH QUALITY CANCER SURVIVORSHIP CARE

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EXPLORING EQUITABLY HIGH QUALITY CANCER SURVIVORSHIP CARE

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ABSTRACT

Evidence of health disparities among cancer survivors is growing. Globally, survivorship models of care are evolving rapidly, yet few consider health and social disparities in their development, limiting access to high quality survivorship care for many. In the current context, Canada's survivorship care systems may privilege some, and not others, to receive high quality survivorship care and optimize health in this context. Understanding the role of disparities in models of care development and access is essential to ensure individual need, rather than social privilege, guides opportunities for high quality survivorship care.

This study aims to improve survivorship care systems by helping clinicians and decision makers to a better understanding of how various factors (e.g. social, political, economic, personal) and survivors' health experiences and health management strategies might shape the development of and access to high quality survivorship care for Canadians with cancer. A nursing disciplinary epistemology, underpinned by pragmatism and informed by critical and intersectional perspectives, served as a framework to explore complexity within survivorship care. A phased qualitative Interpretive Description approach was used to analyze data from three distinct data sources: 1) critical textual analysis of 70+ document sources (e.g., survivorship guidelines, education programs, policies, resources); 2) secondary analysis of multiple transcripts from 19 survivors in an existing data base; and 3) 34 survivor and 12 stakeholder interviews.

Survivors described a gap between their expected and actual survivorship care experiences. This gap was shaped by contextual and structural factors that further marginalized some individuals/groups. Factors shaping this gap at all levels included: individual (e.g., previous experiences, social determinants of health, advanced cancer, age); group (e.g., defining standardized "norms"); and system (e.g. efficiency drivers, underdeveloped guidelines,

exclusionary messaging such as “cancer can be beaten”). Recommendations arising from these findings ranged from strategies to build survivor trust to integrated policies across social and health sectors to promote survivors’ holistic health. This multilayered, intersectoral approach to understanding what shapes survivorship care systems and resources highlights and unravels the complex nature of the issue, helping clinicians and decisions makers find multi-layered approaches for equitably high quality survivorship care.

LAY SUMMARY

Cancer survivors require considerable support, often over an extended period of time. However, not all Canadians have access to such services. Although health care systems are striving to develop supports for cancer survivors, few of the plans include specific attention to the social, political, financial or personal circumstances that affect how different persons experience their cancer survivorship. The purpose of this study was to help health care professionals and those who make decisions about how to deliver care to understand how to provide the highest possible quality survivorship care to all Canadians affected by cancer. An analysis was done of Canadian documents and guidelines for cancer care and survivorship, as well as records of a set of interviews that had previously been done with cancer patients. In addition, 34 cancer survivors and 12 persons who help plan and deliver cancer care were interviewed for the study.

PREFACE

The completion of a dissertation does not always go according to plan, and mine is no exception. In late 2017, my work on it was disrupted by a wonderful professional opportunity to which I could not say no. I thrilled to be hired into the brand new role of Director, Research, Education and Innovation at BC Cancer – the coordinating body for cancer care across the entire province of British Columbia, Canada. This was an interprofessional leadership role designed to establish and evaluate education, knowledge translation and research frameworks and initiatives across the province-wide cancer care services. It was an opportunity to return to the organization from which I had departed under much different circumstances eight years previously, and to be positioned such that I could actually play a meaningful role in enacting the kinds of initiatives that a research project such as this one aspires to inform. Temporarily, as I dove into the work, the dissertation writing was put on hold, although my enthusiasm for and engagement with the ideas within it continued.

In April of 2018, after only 6 months in my dream job, I was diagnosed with glioblastoma. It became clear over the ensuing months that the dissertation in the full scope with which I had intended it, was no longer an option. However, with the assistance of those around me, I have been able to bring together the notes and records that demonstrate the line of reasoning that would have been there within the final chapters had I been able to write them, so that I can bring this process to a close for now. There is, naturally, much more to be written on the topic and many stories to tell on the basis of what I have learned from the people and processes I have studied, and I hope that I will be able to contribute to that.

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My fellow doctoral students and the faculty at the UBC School of Nursing have pushed my thinking far beyond what I thought possible and allowed me to discover new ways to enact my nursing leadership and scholarship. I have also had tremendous guidance and support from my supervisor, Dr. Sally Thorne, and the members of my doctoral supervisory committee, Drs. Colleen Varcoe and Carolyn Gotay. They have insisted that I strive for excellence and relevance in my academic work, and encouraged me at every step of the process. In recent months, when the work became more difficult, a number of others have also stepped up to help with of assorted proofreading, formatting, and related tasks associated with dissertation completion. I want to acknowledge Drs. Fuchsia Howard and Emily Jenkins in this regard, as well as my longtime special friend and colleague Shelley Canning. Organizationally, the School of Nursing has been remarkably supportive of the changing conditions of my program, and the Faculty of Graduate and Post-Doctoral Studies has extended itself to provide compassionate solutions to my program completion challenge.

Finally, I want to express my profound gratitude for being part of an incredible family that has sustained me in every way imaginable. My husband Dr. Michael McKenzie and my beautiful

daughters, Sophie and Molly McKenzie are the centre of my universe, and I will be forever grateful for all they have taught me and all the joy they have brought to my life. We four are blessed to be part of a joyous and large extended family that has meant so much to all of us.

CHAPTER ONE: Introduction

Exploring Equitable High Quality Cancer Survivorship Care

After my very last radiation treatment for breast cancer, I lay on a cold steel table hairless, half-dressed and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead I was sobbing. At the time, I wasn't sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy, and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned and terrified. This was the rocky beginning of cancer survivorship for me."

Elizabeth M., Breast cancer survivor (Hewitt, Greenfield & Stovall, 2006, p. 85).

1.1 Background

Over the past two decades, advances in the detection and treatment of cancer have enabled more people to live longer with a cancer diagnosis than ever before (Canadian Cancer Society, (CCS), 2013). Rather than questioning, "will I live?", at least two-thirds of people diagnosed with cancer in North America ask, "how well will I live?", often shifting the conversation about cancer from victim to survivor (Bell, K., 2010; Leigh, 2007; Zebrack, 2000).

Although technically cured or in long-term remission, many cancer survivors¹ continue to face life-long physical, psychological, sexual, social, and financial challenges after treatment completion, including lingering cancer recurrence and secondary prevention concerns, negatively impacting quality of life (Aziz, 2007; Bellizzi, Keith, Jeffery & McNeel, 2005; CPAC, 2013;

¹ For the purpose of this study, a cancer **survivor** is a person diagnosed with cancer. Cancer **survivorship** refers to the phase in the cancer trajectory, beginning after the completion of primary treatment and lasting for the remainder of one's life (Hewitt et al., 2006; Rowland, Hewitt & Ganz, 2006).

Fosså, Vassilopoulou-Sellin & Dahl , 2008; Ganz, 2009; Gao, Bennett, Stark, Murray & Higginson, 2010; Gifford, Sim, Horne, & Ma, 2014; Gotay & Muraoka, 1998; Hewitt et al., 2006; Jefford et al., 2008; Jones & Grunfeld, 2011; Mao et al., 2007; Mehnert, de Boer & Feuerstein, 2013; Ness et al., 2013). Compounding these challenges, survivors must navigate the specialized oncology and primary care systems, which are described as fragmented, sometimes inaccessible, and “like a maze” (Canadian Strategy for Cancer Control (CSCC), 2002). Numerous factors, such as an overburdened cancer treatment system, growing population of aging survivors with concurrent complex health conditions, increasing prevalence of survivors without primary care providers, a persistent and energetic consumer movement demanding person-centered quality of care and a renewed focus on health promotion have created additional challenges for the development of accessible, equitable, high quality survivorship care within the health care system (Bellury et al., 2011; Canadian Partnership Against Cancer (CPAC), 2007, 2008, 2012b; Casillas & Ayanian, 2011; Feuerstein & Ganz, 2011; Ganz, 2009; Haylock, 2006; Jones & Grunfeld, 2011; Maddison, Asada, & Urquhart, 2011; McCabe et al., 2013). With historical roots in biomedicine, primarily focusing on treating and managing disease, the cancer treatment and primary health care systems demonstrate significant gaps in addressing the multitude of medical and supportive care needs of survivors (Canadian Association of Provincial Cancer Agencies (CAPCA), 2010; Grunfeld & Earle, 2010; McMurtry & Bultz, 2005; Sofaer, 2009).

There is general consensus that the current care of cancer survivors in North America is suboptimal (Canadian Cancer Research Alliance (CCRA), 2017; Hewitt, Bamundo, Day & Harvey, 2007; Hewitt et al., 2006; Malin, Sayers & Jefford, 2011; McCabe et al., 2013; McCabe & Jacobs, 2012; National Academies of Sciences, Engineering and Medicine, 2018; Ristovski-Slijepcevic, 2008). Coordination of care between specialty oncology and primary care systems is disjointed, and there exists a too narrow focus on medical surveillance at the expense of

psychosocial support or health promotion activities. Survivors report lacking necessary information, and that their psychosocial, supportive care and health promotion needs were rarely met (Campbell et al., 2011; Canadian Association of Provincial Cancer Agencies (CAPCA), 2010; Canadian Partnership Against Cancer (CPAC), 2008; CSCC, 2002; Cheung, Neville, Cameron, Cook, & Earle, 2009; Cheung, Neville & Earle, 2010; Grunfeld & Earle, 2010; Hewitt et al. 2006; Hewitt, et al., 2007; Hodgkinson, Butow, Hobbs, & Wain, 2007; McMurtry & Bultz, 2005; Sofaer, 2009). Rarely are the voices of survivors, and in particular those within marginalized groups – in the sense of those population sub-groups known to experience marginalizing conditions within society- considered in the planning of survivorship care models (Ashing-Giwa et al, 2013; Boehmer, Glickman, Milton & Winter, 2012; Boehmer, Miao & Ozonoff, 2011; Boehmer & White, 2012; Brooks, 2009, 2010; CCRA, 2017; CPAC, 2007; Gifford, Thomas, Barton, Grandpierre, & Graham, 2018; Gould et al., 2009; Skinner, 2012).

Along with the growing population of cancer survivors, a new discourse on cancer is emerging, centered on survival rather than death or victimization (Bell, K., 2010; Bell & Ristovski-Slijepcevic, 2013). This new survivorship discourse is presented, particularly within the media, as overwhelmingly positive and “transformative”, highlighting the role of self-care, choice, responsibility and personal autonomy (Bell & Ristovski-Slijepcevic, 2013; Ehrenreich, 2001; Kromm, Smith & Singer, 2007). This survivorship discourse largely has been shaped through media reports, pharmaceutical industry products/messaging and research that excludes the experiences of those who experience marginalizing circumstances within society, setting up for many unrealistic expectations of the experience of surviving cancer. These discourses shape and influence the experience of cancer survivorship and the practice of associated health behaviors, and as well as influence the evolution of survivorship models and resources to address

survivors' and family needs after primary treatment is completed (Bell, K., 2010; 2012; Bell & Ristovski-Slijepcevic, 2013; Sinding, 2014; Sinding & Gray, 2005).

Key elements for quality survivorship care are identified in an influential Institute of Medicine (IOM) report on cancer survivorship (Hewitt et al., 2006), which has been used by most developed countries including Canada to inform the development of survivorship care. These elements include a) prevention, surveillance and detection of cancer spread and new cancers, b) intervention for consequences of cancer and its treatment, and c) coordination of care between specialists and primary care providers (Hewitt et al., 2006). Missing from the report's biomedical, disease and system-focused perspective on quality survivorship care are contextual elements such as customization of care based on survivors' preferences and needs, relational care that is inclusive of the family, a focus on health promotion and wellness, and discussion of health care provider roles other than physicians within survivorship care (Lotfi-Jam, Schofield, & Jefford, 2009; Malin et al., 2009). Further, there is a lack of consensus on a definition of survivorship across this high-profile IOM report and other key survivorship stakeholder groups (e.g. various cancer advocacy groups, research funding bodies, survivorship programs). Some define survivorship as starting at the time of diagnosis with cancer; others suggest survivorship starts at the completion of primary treatment for cancer. Some definitions include the family; others include only individuals with curative disease (Doyle, 2008, 2010; Hewitt et al., 2006; Jefford, 2009; National Coalition for Cancer Survivorship, 2014a; Office for Cancer Survivorship, National Institutes of Health, 2014). These varying definitions have implications for how survivorship care is researched, designed and enacted.

Despite all of these gaps and inconsistencies, many survivors do find their way through the conventional cancer care, primary care and other complementary and lay health care systems, networks and resources to address their survivorship needs, but with significant personal,

physical, emotional, financial, relational, and other costs associated (Campbell et al., 2011; Guy et al., 2013; Jones & Grunfeld, 2011; Rowland, 2008a, 2008b). For many the survivorship “non-system” of care is one more barrier to overcome to achieve optimal health and well-being (Hewitt et al., 2006; Sofaer, 2009; Tirelli, Annunziata, Spina, Dal Maso & Berretta, 2011).

The Canadian Partnership Against Cancer² (CPAC) has set out a pan-Canadian strategy with the goal for *all* Canadians to have access to equitable, person-centred, safe and high quality cancer care (CPAC 2012b, 2014a, 2014b, 2014c). High quality cancer care aligns timely, safe, effective, efficient and equitable resources with survivor needs to achieve desired outcomes such as improved survival, functional status, quality of life and personal cancer experience (CPAC 2012, 2014a, 2014b, 2014c; Feuerstein & Ganz, 2011; Hewitt et al., 2006; Lotfi-Jam et al., 2009; Malin et al., 2011). Increasingly however, health disparities³, have been documented among survivors, particularly those in rural and remote settings, lower socio-economic status, older, advanced disease at diagnosis, Aboriginal groups, and ethnic minorities and immigrants (Ahmed & Shahid, 2012; Barroetavena, 2008; Blinder & Griggs, 2013; CPAC, 2014a; Casillas & Ayanian, 2011; Gotay, Holup & Pagano, 2002; Maddison, Asada & Urquhart, 2011; Pedro, Schumaker, Proto & Hansen, 2012; Sheppard et al., 2010; Wen, Fang & Ma, 2014; White et al., 2013). Documentation of disparities among these groups signals that high quality cancer survivorship care for all Canadians is not being realized (Casillas & Ayanian, 2011). Without

² The Canadian Partnership Against Cancer (CPAC) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership works with cancer experts, charitable organizations, governments, cancer agencies, national health organizations, patients, survivors and others to implement Canada’s cancer control strategy.

³ Health **disparities** are differences that are a result of social processes. Disparities are systematic, produced and maintained by unfair social arrangements, and are potentially remediable. The terms **inequity** and **disparity** are used interchangeably in the literature. In contrast, **inequalities** are differences between groups that may or may not be morally concerning (Whitehead & Dahlgren, 2006).

attention to person-centred care⁴ at the individual level (and the structures and contexts necessary to enact person-centred care within the health and cancer care systems), health disparities may be inadvertently accentuated, especially among those who experience marginalizing conditions within society (Anderson et al., 2009; Epstein, Fiscella Lesser & Stange, 2010; Hankivsky, 2011; Reimer Kirkham & Browne, 2006). These disparities come to light when population-based studies compare survivor access to care and other outcomes that are indicators of high quality survivorship care across groups (Blinder & Griggs, 2013; CPAC, 2007; CPAC 2014a; Laiyemo et al., 2010; Moy et al., 2011; Niu, Roche, Pawlish & Henry, 2013; Weaver, Geiger, Lu & Case, 2013; Wray et al., 2013). T

The complex social, economic and environmental circumstances in which people live also influences options for health behaviors and health care, which, when not taken into consideration in the planning and delivery of survivorship care, may further marginalize individuals and/or groups (Boehmer, Miao & Ozonoff, 2012; de Oliveira et al., 2014; Guy et al., 2013; McNulty, Nail & Block, 2014; Meneses, Azuero, Hassey, McNeese & Pisu, 2012; Paxton et al., 2014; Poll-Franse, Mols, Nijsten, Vissers & Thong, 2012; Wen et al., 2014). The evolving cancer survivorship care system itself, with its biomedical and neoliberal⁵ roots, may act as a structural barrier that promotes inequities for many. For example, the promotion of self-care strategies without the necessary supports to ensure these strategies are contextualized for individuals'

⁴ Person-centred care takes into account the needs of the whole person (i.e. psychological, social, spiritual, informational, practical, emotional and physical), including beliefs, values and goals throughout the cancer trajectory (CPAC, 2014c)

⁵ A neoliberal ideology purports individual free choice and equal opportunity for economic gain, and is prevalent in survivorship care models such as those strategies focused on self-care (Browne, 2001; Coburn, 2004). Neoliberal ideologies negate the social, political and cultural norms and contexts that shape health, creating a problematic illusion that ill health springs from the characteristics or behaviors of individuals (Dean & Kickbush, 1995). This ideology may constrain individuals' ability to enact agency (capacity to engage in deliberate action) if the context and structures within which individuals are imbedded are not also attended to (Foster & Fenlon, 2011; Sherwin, 1998).

social, economic and environmental circumstances can create a gap between those who are able to independently take up self-care strategies and those who are not due to marginalizing circumstances (e.g. language, culture, poverty).

With the goal of optimal health in view, equity means that peoples' needs, rather than their social privileges, ought to guide the distribution of opportunities for optimal health and well-being (Ahmed & Shahid, 2012; Baum, Begin, Houweling & Taylor, 2009). Therefore, any survivor with unmet needs, including those with social, economic, educational or other privileges, may be at risk for health disparities. Stepping beyond the "have/have-not" binary (i.e. disadvantaged versus advantaged groups), strategies such as an intersectional⁶ lens may be used to explore how the multitude of factors, conditions, contexts and structures that layer and intersect to promote and minimize disparities in the survivorship population (Dhamoon, 2011; Hankivsky, 2011). This knowledge maybe then used to inform the design of models of care and resources that take into account these factors, conditions, contexts and structures to promote equitable access to high quality care for all survivors.

Oncology Nursing, the professional disciplinary lens through which this dissertation is framed, has an ethical and social justice⁷ imperative to support and advocate for optimal health for individuals and aggregates (Canadian Association of Nurses in Oncology (CANO/ACIO), 2006; Canadian Nurses Association, 2009, 2010, 2013). Nurses are situated "at the intersection of

⁶ Intersectional approaches emphasize the way in which differences work through one another to produce something unique and distinct (Hankivsky, 2011). Applied to the current study, intersectionality operates as a heuristic to recognize the complexities inherent within survivorship care, and to explore how the intersection and layering of multiple, complex, and varied axes of differentiation (e.g. subjective, experiential, economic, political) may come together to produce something unique and distinct from any one form of difference standing alone (Dhamoon, 2011; Dhamoon & Hankivsky, 2011; Hankivsky, de Leeuw, Lee, Vissandjee & Khanlou, 2011).

⁷ Social justice begins with understanding differences between subgroups, particularly power, and highlighting the structural conditions that shape inequities (Buettner-Schmidt & Lobo, 2012; Reimer Kirkham, 2006; Young, 1990).

public policy and personal lives; they are, therefore, ideally situated and morally obligated to include sociopolitical advocacy in their practice” (Falk-Rafael, 2005, p. 222). Nurses use frameworks and theories to understand the complexities inherent within individuals, and acknowledge the intersection and layering of social, political, economic, historic, structural and other factors that shape and influence health in individuals and populations (Doane & Varcoe, 2005; Johnson & Ratner, 1997; Purkis & Bjornsdottir, 2006; Thorne et al., 1998; Thorne & Sawatzky, 2014). Through the explication of how the layering and interplay of these various factors shape survivorship care, nursing’s disciplinary knowledge may help to untangle and acknowledge the complexities in survivorship care of individuals and aggregates/populations. As an action-oriented profession, nursing’s disciplinary knowledge also helps to move beyond simply describing, framing recommendations and possibilities for action that address the complexities inherent in survivorship care (Thorne, 2008b, 2011; Thorne & Sawatzky, 2014).

In general, research and discourses that critically examine how social, political, economic and other factors layer and intersect to influence access to and use of equitable high quality cancer survivorship care have been not yet been examined in great detail (see for example, Bell, K., 2010; Bell & Ristovski- Slijepcevic, 2013; Sinding & Gray, 2005). Moreover, there have been no studies that move beyond description of the issues and challenges, to provide *possibilities, recommendations and/or principles for action* to create equitable survivorship care models and resources that recognize the complexities inherent in survivorship care.

1.2 Central Problem and Purpose of the Study

Models of survivorship care to date have been significantly shaped by a variety of factors, which, if left unchecked, will continue to influence how survivorship models of care and resources are developed, enacted and evaluated (Barry, 2006; Hollenberg & Muzzin, 2010; Jones & Grunfeld, 2011; Rowland, 2008; Sinding & Gray, 2005). Uncritical replication of current

survivorship care models may further marginalize vulnerable groups⁸ and limit opportunities for optimal health of survivors at the individual and aggregated levels. Contextual knowledge is required to inform the development of future survivorship models of care and resources, taking into consideration the complexities involved in the layering and intersection of factors that shape survivors' agency both at an individual and population level as well as offering direction for action in the development of survivorship care models and resources.

The purpose of this study is to explore and explain how the layering and intersection of social, political, economic and personal factors, and health experiences and health management strategies shape and influence the development of and access to equitable high quality survivorship care for Canadians with cancer. Drawing upon a variety of perspectives, sensitized by an intersectional lens (Hankivsky, 2011) and guided by Nursing's disciplinary epistemology as the theoretical framework, I use a qualitative interpretive description (Thorne, 2016) approach to inquiry as the methodological orientation for this study. Through this process, I aim to expand our understanding of how current cancer survivorship approaches to care may inadequately address the full range of survivors' needs required to achieve high quality care. On the basis of this process, I hope to make recommendations for action regarding the development of high quality cancer survivorship resources and models of care that take the equity challenge into consideration.

1.3 Research Questions

The problem to which this study is directed is the current challenge associated with conceptualizing the nature of the cancer survivorship phenomenon in Canada and constructing a

⁸ Vulnerable groups may include those at risk of poor health outcomes as a consequence of systematic barriers for equity in access to quality care that addresses their unique needs. Vulnerabilities are produced as a result of historical, economic, political, social and other structural factors, rather than a characteristic or weakness of the individual or population (Barroetavena, 2008).

coherent and equitable approach to addressing it. Toward advancing our understanding of this challenge, the overarching research question guiding this study will be:

How can cancer survivor and system stakeholder⁹ perspectives inform our understanding of what is needed to ensure both high quality and equity in cancer survivorship care systems in Canada?

Subsumed under this umbrella question is a set of subsidiary questions that reflect the multi-layered inquiry and analysis required to develop a more comprehensive understanding of the survivorship challenge across individual and aggregate perspectives.

1. How do cancer survivors describe and explain their access to and experience of survivorship care?
2. How do cancer survivors and system stakeholders understand various social, economic, political and personal factors that may influence survivors' access to and experience of survivorship care?
3. How do survivors and system stakeholders describe an envisioned system of care that promotes high quality survivorship care?
4. What approaches do survivors and system stakeholders recommend to promote the development of high quality survivorship resources and models of care that addresses survivors' needs at both an individual and aggregate level?

⁹ **System stakeholders** are individuals with broad experience and expertise in Canadian cancer survivorship care system(s), including insights into the factors, conditions, contexts, and structures that have shaped/have the potential to shape current and future survivorship care.

CHAPTER TWO: Literature Review

2.1 Introduction

In this chapter, I review the literature to provide a context within which to explore factors that shape and influence cancer survivorship care, as well as survivors' health management strategies and experiences of engaging with the survivorship care system. Using a critical integrative approach, I review a range of empirical and theoretical literature across nursing, medicine, epidemiology, sociology, psychology, anthropology, rehabilitation medicine, and philosophy. Select popular literature also is reviewed to understand the experience of accessing and interacting with cancer survivorship care as described by survivors themselves and portrayed in the media.

I begin by situating cancer survivorship within the cancer trajectory and explore the associated definitional challenges as well as describe survivors' needs. Through a review of the Canadian context for cancer survivorship care, I explore concepts of equity and quality, including an assessment of how well the current survivorship care system measures up to deliver equitable high quality survivorship care. To gain new insights and discover possibilities to evolve cancer survivorship care, I review non-cancer models and approaches to care, as well as health equity strategies employed in other non-cancer care systems and settings. I describe and explore survivor's perspectives regarding their experiences and health management strategies within the current survivorship care system to uncover gaps and opportunities to further evolve patient-centred approaches to survivorship care. Finally, to provide a historical, social and political context to better understand how survivorship care has been shaped, and consider possibilities for future action, I deconstruct and critically examine the metanarratives and the ideologies underpinning survivorship care.

2.2 Situating Cancer Survivorship

In Canada, almost half of the population will develop cancer in their lifetime, and one quarter will die of their disease (Canadian Cancer Statistics Advisory Committee, 2018, p. 6). Although cancer has surpassed heart disease as the leading cause of death in Canada, more people are living longer with cancer than ever before. In 2013, approximately 63% of adults in Canada were alive five years post-diagnosis of cancer, an increase in survival rate of almost 13% over the past 30 years (CCS, 2013). In 2000, cancer accounted for \$2.6 billion in direct health care costs, and \$14.8 billion in indirect costs from loss of productivity and premature death (Institute of Health Economics, 2008).

At the beginning of 2009, 838,724 people in Canada were living with a diagnosis cancer, or about 2.5% of the population, with breast and prostate cancer accounting for about 40% of these cancers (CCS, 2013). By 2036, the Canadian population is expected to reach 47 million, with a doubling of the senior population (Statistics Canada, 2009). As cancer in adults is a disease of aging, the expected population increase will challenge health care systems to find new ways to optimally and efficiently address the needs of the growing number of people living with cancer.

Although there are over 200 types of cancer, a complex array of factors interacts to determine the survivorship trajectory for any individual survivor. For example, certain cancers such as pancreatic, liver, lung and head and neck cancer are generally associated with greater morbidity and shorter survival times (American Cancer Society, 2011; CCS, 2013). Risk factors for development of these cancers can include lower socioeconomic status (SES), being male, alcohol use, smoking and viral infections such as Hepatitis B & C (Blinder & Griggs, 2013; CCS, 2013). Conversely, breast and prostate cancer, while diagnosed more frequently, generally are associated with longer survival times and less morbidity when compared to pancreatic, liver, lung and head

and neck cancer (CCS, 2013). While the biology of the cancer itself accounts for some of the morbidity and mortality, some of this also can be explained by the social, political, historical and economic context in which individuals with these types of cancer live (Casillas & Ayanian 2011; Cona, Harris, Lawrence & Southall, 2010; Dunn, Agurs-Collins, Browne, Lubet & Johnson, 2010; Niu, Roche, Pawlish, & Henry, 2013; Polacek, Ramos & Ferrer, 2007; Tompa, 2011). Racialization¹⁰, sex, gender, minority status, poverty and low socio-economic status and rural and remote geography, for example, all have been demonstrated to impact the stage of diagnosis and access to quality treatment, which in turn, impacts quality of life and survival (Ayanian, 2010; Kagawa-Singer, Dadia, Yu & Surbone, 2010; Lannin et al., 1998; Lantz et al., 2006; Laiyemo et al., 2010; Meneses & Benz, 2010; Niu et al., 2013; Paskett et al., 2011; Pedro et al., 2012; Sheppard et al., 2010; Skinner, 2012; Weaver, Geiger, Lu & Case, 2013; Wray et al., 2013). The complex social, economic and environmental circumstances in which people live also influences options for health behaviors and health care (Boehmer, Miao & Ozonoff, 2012; de Oliveira et al., 2014; Guy et al., 2013; McNulty, Nail & Block, 2014; Meneses, Azuero, Hassey, McNees & Pisu, 2012; Paxton et al., 2014; Poll-Franse, Mols, Nijsten, Vissers & Thong, 2012; Wen et al., 2014). “The receipt of health care is the outcome of many different complex processes, of which all need to be recognized if access is to be properly understood” (Dixon-Woods et al., 2006, p. 7).

2.2.1 Stepping back: Who is a survivor? To begin to unravel the complexities associated with how best to meet survivors’ needs and to develop high quality equitable models of survivorship care, it is important to understand who is considered a cancer survivor, and what is the difference between *survivors* and *survivorship*. While most experts would agree that *survivorship* constitutes a distinct phase in the cancer trajectory, beginning at the end of primary

¹⁰ Racialization refers to racial injustice, or discrimination based on race/belonging to a racial or ethnic group, rather than the biological concept of race (Kagawa-Singer et al., 2010).

cancer treatment and continuing to the end of one's life (Hewitt et al., 2006; Rowland, Hewitt & Ganz, 2006), there is little consensus regarding the term *survivor*. Differing perspectives and definitions of the term *survivor* among advocacy groups, organizations, care delivery services, funding bodies, and survivors themselves highlight how the term is constructed by historical, biomedical, social, political, cultural and personal forces (Bell, K., 2010, 2012; Bell & Ristovski-Slijepcevic, 2013; Doyle, 2008; Feuerstein, 2007a, 2007c, 2007c; Khan et al., 2012; Malin et al., 2011; O'Brien, 2014; Peck, 2008; Sulik, 2013). A review of these forces influencing how the term survivor is constructed reveals some of the (hidden) tensions and complexities that may influence how survivor *care* is defined, enacted and evaluated.

Historically, driven by the biomedical model¹¹ that focuses on eradicating *disease* from the body to achieve a cure (Capra, 1982), the term *survivor* was used to refer to individuals who have had a diagnosis of cancer and remained disease-free for at least five years (Rowland, 2007; Twombly, 2004; Marcus, 2004). Over the last 20 years this definition has evolved to include a broader focus on the people and their experience of cancer, and in some instances, their family friends and caregivers, rather than a singular focus on the absence of disease or achievement of a cure.

Fitzhugh Mullan, an influential physician, cancer survivor and advocate was among the first to pull away from the dominant biomedical view of equating being a survivor with achieving a cure. Instead, he proposed three phases or “seasons of survivorship”: a) *acute survival*, which includes the period after diagnosis in which the individual is focused on surviving the treatment,

¹¹ The Biomedical model is often synonymous with “the medical model”. It is situated within the Cartesian reductionist paradigm (everything can be reduced to its smallest parts to be understood); the human body is regarded as a machine; disease is the focus rather than health; the doctor's task is to repair the machine. The Biomedical system is the organization of social, political, practical and scientific structures within which to practice the biomedical model (Capra, 1982).

b) *extended survival*, which occurs when treatment is complete and is dominated by dealing with the physical and psychological effects of diagnosis and treatment and c) *permanent survival*, in which the individual lives the remainder of their life dealing with fears of recurrence or living with metastatic disease, and late/long term effects of treatment (Mullan, 1985). In Mullan's view, everyone diagnosed with cancer, regardless of curative or palliative intent, is considered a survivor. Further, he offered a beginning perspective on the experience of living with, through, and beyond cancer treatment.

Within North America and some developed countries, innovations in cancer treatment that prolong people's lives, coupled with a resurgence of a self-help and patient empowerment approach to health, has spurred on survivor-led advocacy groups such as the National Coalition for Cancer Survivorship (NCCS, 2014a) to reframe the experience of cancer from *victim* to *survivor*. Moving away from the concept and language of victim and locating the experience of being a survivor within every person's reach, they argued that, "from the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor" (NCCS, 2014a). The Office of Cancer Survivorship of the National Cancer Institute added, "family members, friends, and care-givers are also impacted by the survivorship experience and are therefore included in this definition" (OCS, NCI, 2014).

Survivors' perspectives regarding who is a cancer "survivor" are mixed and may impact how the individual engages with the health care system, particularly after primary treatment has ended (Little, Paul, Jordens & Sayers, 2002; Park, Zlateva & Blank, 2009). These perspectives range from those who identify as a survivor from the time of diagnosis throughout the rest of their lives, some who some who call themselves "thrivers" at the point of completion of primary cancer treatment, and yet others who completely reject the notion of survivor, equating the label with surviving a trauma (Bell & Ristovski-Slijepcevic, 2012; Bellizzi & Blank, 2007; Deimling,

Bowman & Wagner, 2007; Ehrenreich, 2001; Kaizer, 2008; Khan et al., 2011; Khan et al., 2012; McGrath & Holewa, 2012; Zebrack, 2000). Understanding the individuals' perspective regarding the association or affiliation with the term survivor, and the reasons underpinning this perspective, will be important to explore when designing new models of survivorship care that are inclusive of diverse perspectives and that promote equity.

In this study I use both terms, *survivorship* and *survivor*. *Survivorship* refers to the phase in the cancer trajectory that begins after primary cancer treatment ends and continues throughout the remainder of one's life. *Survivor* refers to a person living with a diagnosis of cancer. Both concepts are necessary to fully explore equitable high quality survivorship care; the survivorship phase defines points in time; a survivor experiences these points in time through their own unique perspectives, influenced by a variety of structural, environmental, social, and other factors that layer and intersect to shape this experience of living as a survivor, during the survivorship phase of the cancer trajectory¹².

2.2.2 What are the needs of cancer survivors? Although the cancer survivorship phase is generally considered to start after primary cancer treatment has ended, the decisions, experiences, treatments and interventions that take place earlier in the cancer trajectory (i.e. at diagnosis and during treatment) have a profound influence on treatment outcomes and the quality of life of survivors after primary treatment ends (Adler & Page, 2008; Beesley et al., 2013; Hewitt et al.,

¹² Although each individual diagnosed with cancer is infinitely complex, there exists a common trajectory that most people follow upon diagnosis with cancer. After diagnosis, primary treatment will take place as needed (e.g. chemotherapy, radiation therapy, surgery, supportive care intervention). Upon completion of primary treatment, the survivorship phase begins. During this phase, individuals may follow a variety of different and sometimes overlapping pathways over the remainder of their lives. These pathways may include a) require no further active treatment (i.e., deemed cured), b) receive ongoing maintenance therapy to reduce risk of recurrence (e.g. anti-hormonal therapy) or manage stable metastatic disease (e.g. Herceptin for Her2 positive breast cancer), c) receive ongoing supportive care to manage late and long term effects as a result of primary treatment, and/or d) supportive end-of-life care (CPAC, 2012) (see Figure 1)

2006; Hewitt et al., 2007; Pigott et al., 2009). Cancer and its treatment can affect almost every body system to produce late and long term effects such as infertility, sexual dysfunction, cognitive dysfunction, pain, fatigue, neuropathy, sleep disturbances, functional limitations, nutritional challenges and cardiac and respiratory toxicities (Aziz, 2007; Beasley et al., 2011; Boyes, Hodgkinson, Aldridge & Turner, 2009; Burton, Fanciullo, Beasley & Fisch, 2007; Butow et al., 2013; Carver et al., 2007; Correa & Ahles, 2008; Fossa et al., 2008; Ganz, 2009; Hodgkinson et al., 2007; Jones & Grunfeld, 2011; Lee et al., 2006; Loren et al., 2013; Miller & Triano, 2008; Polomano & Farrar, 2006; Roscoe et al., 2007; Shi et al., 2011; Sweeney et al., 2006). Increased risk for weight gain, obesity and diabetes are also experienced by many survivors as a result of primary cancer treatments, which in turn increases the risk of recurrence and secondary cancers (Demark-Wahnefried, 2001; Kroenke, Chen, Rosner & Holmes, 2005; Ng, Kenney, Gilbert & Travis, 2010; Rock & Demark-Wahnefried, 2002). Coronary artery disease and osteoporosis are also common late term effects of primary treatment, and can interfere with physical activity and activities of daily living (Camp-Sorrell, 2006; Carver et al., 2007; Sweeney et al., 2006; Weaver et al., 2013). Cancer survivors are twice as likely to experience cardiovascular disease than the general population (Burnett, Kluding, Porter, Fabian & Klemp 2013; Camp-Sorrell, 2006; Gaya & Ashford, 2005; Monsuez, 2012; Moslehi, 2013), and overall report lower quality of life than those without a history of cancer (Ferrans, 2004; Ferrell & Hassey-Dow, 1997; Gao & Dizon, 2013; Jensen et al., 2013a; Kouri & Keating, 2011; Meneses & Benz, 2010; Wen, Fang & Ma, 2014).

Psychosocial, financial, and employment concerns also arise in the survivorship phase, and may significantly affect quality of life (Miller, 2012, 2014). Fear of recurrence, anxiety, distress, and issues related to altered body image and/or sexual dysfunction are commonly reported by survivors (Adler & Page, 2008; Dizon, Suzin & McIlvanna, 2014; Hodgkinson et al., 2007;

Livaudais et al., 2010; Ness et al., 2013; Pelusi, 2006, 2007; Thewes et al., 2012; van de Poll-Franse et al., 2011). In studies with breast and colorectal cancer survivors, approximately one-third report clinical levels of anxiety and depression at five years post treatment (Mehnert & Koch, 2008; Tsunoda et al., 2005; Kornbith & Ligibel, 2003; Knobf, 2011). These psychosocial concerns may impact relationships, engagement with one's community and social support system, and employment. For many survivors, financial worries abound as they are either unable to work or are limited in the amount and complexity of work in which they may engage due to the lasting physical and psychosocial effects from their cancer treatment (Earle et al., 2010; Feuerstein, 2009; Guy et al., 2013; Meneses, et al., 2012; Quinlan, 2011; Taskila et al., 2009). Family members and caregivers are also affected throughout the survivorship phase, experiencing distress, fatigue and increased role demands, challenging the functioning of the family unit as a whole (Bowman, Rose & Deimling, 2005; Hollenbeak, Short & Moran, 2011; Lewis, 2006; Marshall, 2010; Muhamad, Afshari & Kazilan, 2011).

Of special concern are the increasing numbers of elderly (greater than 70 years) cancer survivors, who represent approximately 43% of individuals living with cancer in Canada (CCS, 2013). These older survivors may also have comorbid conditions and general functional decline due to the normal aging process, may not tolerate cancer treatments well and experience more immediate and long-term effects, and may have fewer social supports and economic resources (Bellury et al., 2011; Bellury et al., 2012; Garman, Pieper, Seo & Cohen, 2003; Giacalone et al., 2013; Jensen et al., 2013; Mandelblatt et al., 2003; Sweeny et al., 2006). Despite this increasingly prevalent population of aging cancer survivors, interventions to address late and long-term effects have been derived from evidence that excludes survivors older than 65 years. As such, we do not know if interventions developed for a younger population are relevant and effective for this older population, making developing new models of care and resources to address the needs of this

population more challenging (Bellury et al., 2013; Jensen et al., 2013; Jones & Grunfeld, 2011; Mandelblatt et al., 2003).

It is clear that cancer survivors experience a multitude of complex and long lasting sequelae that require early, proactive, and coordinated care to promote optimal health and quality of life for survivors post treatment. However, the (Canadian) cancer care system, models of care and available resources currently are not optimally developed to address these needs in an equitable manner for all Canadians (Hewitt et al., 2006).

2.3 Cancer Survivorship: The Canadian Context

Prior to the publication of the Institute of Medicine's (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in transition* (Hewitt et al., 2006)¹³, survivorship was not considered a distinct phase in the cancer trajectory in North America. Instead, individuals completing primary treatment were congratulated for achieving this end-of-treatment milestone and sent back to their primary care provider to "get back to normal" or receive palliative/end-of-life care. Many survivors with more complex situations continued to be seen by their oncologists after primary treatment ended, but no overarching guideline existed to direct this allocation of specialist versus primary care physician resource. Communication between oncologists and primary care providers regarding the health care needs of survivors rarely, if ever, occurred. No clear practice guidelines, models of care, or knowledgeable health care providers in the primary care system were consistently available to support cancer survivors in optimally meeting their physical, psychosocial, practical, informational and health promotion and cancer recurrence/secondary cancer prevention needs (CAPCA, 2010; Canadian Partnership Against Cancer (CPAC), 2012b;

¹³ A committee was established at the Institute of Medicine (IOM) of the National Academies in the US to examine the range of medical and psychosocial issues faced by cancer survivors and to make recommendations to improve their health care and quality of life. Although specifically targeting the US population, Canadians were involved as stakeholders (Hewitt et al., 2006).

Cancer Care Nova Scotia, 2004; Hewitt et al., 2006; Howell et al., 2012; Ristovski-Slijepcevic, 2008).

Today in Canada, twelve years since the IOM's *Lost in Transition* report (Hewitt et al., 2006) that included recommendations to improve the quality of survivorship care in North America (see Table 1), the current model of survivorship care has evolved only minimally. The Canadian Partnership Against Cancer (CPAC)¹⁴, an independent organization funded by the federal government to accelerate action on cancer control¹⁵ for all Canadians, has led the implementation of a number of survivorship action strategies, based on the IOM (2006) recommendations (CPAC, 2012b). Leading these action strategies is a subgroup within CPAC, the National Survivorship Working Group (NSWG), Cancer Journey Portfolio¹⁶, whose mandate is to rebalance the focus of survivorship care from a predominantly tumour-centred focus to a patient-centred approach¹⁷.

Starting with establishing a pan-Canadian survivorship agenda (CPAC, 2008; Ristovski-Slijepcevic, 2008), the NSWG has since facilitated the development and testing of survivorship care plan templates (CancerBridges, 2011; Scalzo, 2009), made recommendations for the organization and delivery of survivorship services (Howell et al., 2011), published a psychosocial supportive care best-practice guideline (Howell et al., 2011), established and

¹⁴ CPAC 's vision is to be a driving force to achieve a person-centred focused approach that will help prevent cancer, enhance the quality of life of those affected by cancer, lessen the likelihood of dying from cancer and increase the efficiency of cancer control in Canada (CPAC, 2012b, 2014c).

¹⁵ A national cancer control program lowers cancer incidence and improves the quality of life for cancer patients and their families, no matter what resource constraints a country faces (Elwood & Sutcliffe, 2010).

¹⁶ National Survivorship Working Group (NSWG) consists of survivors, advocacy group leaders, clinicians, researchers, educators and policy makers. The group is co-led by two long term survivors, to ensure the survivor voice is central in the work and resources produced by the group.

¹⁷ A patient-centred approach takes into account the needs of the whole person (i.e. psychological, social, spiritual, informational, practical, emotional and physical) throughout the cancer trajectory (CPAC, 2014c).

evaluated a national internet-based psychosocial support program (i.e. CancerChatCanada, Stephen et al., 2013), implemented education programs for survivors (i.e. Cancer Transitions, Ward et al., 2010) and for the family of cancer survivors, completed an environmental scan and literature review to inform future return to work projects and tested of a variety of models of care including new roles such as patient navigators (CPAC, 2010). A national research agenda with priorities for survivorship care was also established (CPAC, 2009).

The uptake of these resources and models of care across the country has been variable, influenced by political, economic, social and in some cases patient advocacy factors (CPAC, 2012b; Cheung, Neville, Cameron, Cook & Earle, 2009; Coyle et al., 2011; Coyle et al., 2014; Grunfeld & Earle, 2010; Grunfeld, Earle & Stovall, 2011a; Grunfeld et al., 2011b; Kendell, et al., 2017; Luctar-Flude, Aiken, McColl & Tramner, 2018; Smith, Singh-Carlson, Downie, Payeur & Wai, 2011; Tomasone et. al, 2017). For example, some cancer treatment centres have begun to include face to face and virtual cancer survivorship programs and clinics as an option for survivors with complex needs at the end of primary treatment (see for example, Princess Margaret Hospital (2014); University Health Network ELLICSR (2010)). Others offer a six-week educational program at the completion of primary treatment to learn new lifestyle skills for health promotion and cancer prevention (see for example, Cancer Transitions Program, Prince Edward Island Cancer Treatment Centre). Some have implemented versions of survivorship care plans to facilitate communication between specialist and primary care providers (see for example, CancerBridges, 2011; Fitch et al., 2014). Primary care physician networks for those with large cancer survivor patient populations have been established in some provinces (see for example, Family Practice Oncology Network (2014) in British Columbia) providing education and professional support to primary care physicians to meet the needs of cancer survivors in the community. A number of organizations have implemented Nurse Practitioner and/or Nurse

Navigator roles to ease the transition between end of treatment and primary care (see for example, CPAC, 2010; Cancer Care Nova Scotia, 2004; Franco et al, 2016; Fillion et al, 2012; Nova Scotia Health Authority Cancer Care Program, 2018). This is important and foundational beginning work to move the national survivorship agenda forward. However, without a *coordinated* approach to development, dissemination and uptake of these resources and models of care, there remain significant barriers to survivors becoming aware of, accessing, and navigating among these resources and models of care. Further, there may be some significant challenges in moving forward with these programs, resources, roles and models of care to achieve *equitable quality* survivorship care for ALL Canadians.

2.3.1 Exploring equity in survivorship care. At this point, I briefly discuss the concepts of equity, disparity and justice in cancer survivorship care to more fully inform a critical perspective and discussion regarding the current state of survivorship care and what we can learn from this to move forward. Dialogues about equity must be framed within the broader concept of justice (fairness), differentiating *social* justice from *distributive* justice. Although social justice begins with understanding differences between groups, it also highlights the conditions that shape disparities (Young, 1990).

...*Social* draws our attention to the application of justice to social groups, brings into focus how justice and injustices are sustained through social institutions and social relationships; and highlights the embeddedness of individual experience in a larger realm of political, economic, cultural, and social complexities (Reimer Kirkham & Browne, 2006, p. 325).

Distributive justice, while also about fairness, deals with the allocation of resources, commonly based on neo-liberal, economic and biomedical reductionist foundations for re-distributing and improving access to resources. Attention to distributive justice alone ignores the social interconnectedness of individuals and the influence of structures (e.g. health care

institutions) that may subtly oppress individuals and groups (Pauly, 2013; Reimer Kirkham & Browne, 2006). In the cancer survivorship context, an example of distributive (in)justice includes promoting access to survivorship clinics attached to cancer treatment centres (which are geographically located in urban settings), thereby overlooking the needs of survivors in rural and remote settings.

According to the World Health Organization, *health equity* is “the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically” (Solar & Irwin, 2010, p. 12). Health, as a social phenomenon, is shaped by a complex interplay of structural (e.g., socioeconomic, political and historical context; socioeconomic position) and intermediary factors (e.g., material circumstances, biological factors, behaviors, psychosocial factors, health system) which impacts health equity (Solar & Irwin, 2010; also see Figure 2). Health *disparities*, then, are health differences that are socially produced, systematically distributed across a population, unfair, and potentially remediable (Whitehead & Dahlgren, 2006).

With any discussion about fairness and equity, a few words about the concept of power are necessary. While some conceptualizations of power denote domination, oppression and in some cases, violence (i.e., as in structural violence, where political and economic structures can cause injury to people) (Farmer, 2003), power can also be conceptualized creatively and in the context of other factors influencing health. Drawing from Foucault’s perspective, power is everywhere, comes from everywhere and can’t be “possessed, held, acquired, seized or shared, but only exercised” (Foucault, 1990, p. 92). Although it may not be the only force underpinning the causes of disparity, its ubiquity makes uncovering and acknowledging it a key strategy in any attempt to promote health equity. Conceptualized in this manner, it is possible to express and empower human agency, even in those individuals facing marginalizing conditions within society (Mouffe,

1996). The concept of power, and its relationship to structure and agency, is discussed in more detail later in this dissertation in the discussion on theoretical frameworks.

2.3.2 Are we on the right path to equitable high quality survivorship care? With an equity perspective in place, I return to the discussion about the state of survivorship care in Canada. The concepts of equity and justice have begun to be addressed within the evolving survivorship agenda in Canada. In a discussion paper, *Improving and minimizing disparities for underserved populations* (Barroetavena, 2008), which was a result of a *National forum on cancer care for all Canadians: Improving access and minimizing disparities for vulnerable populations in Canada* (CPAC, 2007), a number of principles were outlined and recommendations made including integrating concepts of diversity and equity as core values underlying a coordinated national cancer control strategy for all Canadians (Barroetavena, 2008, see Table 2). Broadly, these principles include creating partnerships, networks and sharing capacity across CPAC working groups to address inequities within our cancer care system; and to facilitate implementation of national strategies to monitor health disparities and evaluate effectiveness of programs and services in meeting the needs of underserved populations across the cancer care continuum (Barroetavena, 2008; CPAC, 2007).

While not specific to the survivorship phase of the cancer trajectory, the principles and recommendations in the discussion paper offer some helpful direction as well as potential challenges to moving toward an equitable survivorship agenda in Canada. A strength of this discussion paper is the reiteration of key principles guiding the Canada Health Act (1984) and the First Ministers' Accord on Health Care Renewal (Health Canada, 2003), that promises high quality, effective, patient-centered and safe care accessible to all on the basis of need, rather than ability to pay or influenced by where they live in Canada. Despite having laid out this equity lens for use in cancer care in Canada, the CPAC discussion paper heavily focuses on identifying

“vulnerable populations”¹⁸, setting up a binary foundation of “have/have not” for developing services and care models. While it is important to consider the specific needs of these vulnerable groups and ensure services are designed and available to meet their needs, it is also important to consider their needs in the context of ALL Canadians to ensure equitable and quality care for all. Recommendations in this discussion paper are heavily focused on identifying these “have not” groups and improving access to care (distributive justice) for these groups, potentially at the expense of quality care that is designed to meet their unique needs (social justice). There is some suggestion in the report that structural factors (e.g. poverty, geography, language, literacy, communication, culture) may intersect to influence quality of care, but access to care within the cancer care system is the only structural factor addressed.

The Barreotavna (2008) is discussion paper, while aiming to improve quality and equity in survivorship care, seems to inadvertently highlight some of the unhelpful repeated patterns across numerous reports, services and resources designed for cancer survivors. One might argue that underpinning the principles and recommendations of this discussion paper are biomedical and neoliberal¹⁹ influences – ideas largely carried over from the cancer treatment system and

¹⁸ Vulnerable populations are defined in this discussion paper as those experiencing systematic barriers to equity in access to health care services. These individuals are at risk of poor health outcomes as a result of failure of the health and social system to meet the needs of various populations. Examples of persons who are at risk of poorer health outcomes, and the different factors (poverty, rural/remote location, immigrant, language and cultural barriers, transportation barriers) may intersect and further influence the quality of care. Underserved/vulnerable populations may include, but are not limited to: First Nations, immigrants, refugees, injection drug users, street youth, homeless people, ethnically diverse populations, those with disabilities, people who do not speak or read either of Canada’s official languages, sex trade workers, people with alternate sexual orientations, as well as people with socioeconomic challenges and those with mental illness (Barroetavena, 2008).

¹⁹ A neoliberal ideology assumes individual free choice and equal opportunity for economic gain (Browne, 2001; Coburn, 2004) and seems to be playing a role in survivorship care models such within as those that focus on self-care. Neoliberal ideologies discount the social, political and cultural norms and contexts that may shape health, creating a problematic illusion that ill health springs from the characteristics or behaviors of individuals (Dean & Kickbush, 1995). This ideology may constrain an individuals’ ability to

replicated in the survivorship phase of cancer care. If left unchecked, these ideological positions may continue to promote a survivorship care system that is focused on grouping people according to their vulnerabilities, strictly focusing on disease surveillance and increasing their access to survivorship care (distributive justice), rather than their voiced needs as complex individuals living with cancer (social justice). Further, this focused attention to vulnerabilities draws attention away from uncovering and addressing the structural factors influencing these vulnerabilities, as well as strategies to enhance the agency of individuals.

2.4 High Quality Cancer Survivorship Care

Optimal quality survivorship care has been the topic of much discussion over recent years. As has been mentioned, high quality care aligns timely, equitable, effective, relevant and meaningful resources with survivor needs to achieve desired outcomes (Feuerstein & Ganz, 2011; Hewitt et al., 2006; Lotfi-Jam et al., 2009; Malin et al., 2011). In addition to improving disease-free and overall survival as key outcomes, functional status, quality of life, and the personal cancer experience are critical yet often overlooked outcomes for survivors as they deal with the symptom burden and functional limitations that significantly impact their quality of life (Arora, 2009; Feuerstein & Ganz, 2011). High quality care uses a patient-centered approach that includes attention to the whole person, addressing physical, psychological, emotional, social, spiritual, informational, and practical needs of survivors in a way that is inclusive of their beliefs, values and goals for health and well-being (CPAC 2014b, 2014c).

A number of frameworks and landmark reports offer some direction regarding characteristics of health care systems that support quality care. The Institute of Medicine (IOM, 2001) Committee on Health Care Quality in America designed essential features of quality care,

enact agency (in the sense of capacity to engage in deliberate action) if the context and structures within which individuals are imbedded are not also attended to (Foster & Fenlon, 2011; Sherwin, 1998).

including basing care on continuous healing relationships, customization of care based on patient needs and values (and anticipation of those needs), patient choice and control, shared knowledge and free flow of information, evidence-based decision making, safety, transparency, continuous decrease in waste and cooperation among health professionals. Building upon these characteristics to contextualize and operationalize for the cancer survivorship population, nine recommendations and four essential components of quality survivorship care were established in the IOM (2006) report, *From cancer patient to cancer survivor: Lost in Transition* (Hewitt et al., 2006). The nine recommendations focus on key strategies and resources within health care systems to promote survivorship care, such as, for example, using survivorship care plans as a principle mode of communication, using evidence based clinical practice guidelines; advocating for improved policies for return to work and adequate and affordable health insurance (see Table 1 for complete list of recommendations).

The essential components identified within the IOM (2006) report offer direction for the care of individual survivors. These essential components include a) *prevention* of recurrent and new cancers and other late effects, b) *surveillance* for cancer spread, recurrence or secondary cancers; assessment of medical and psychosocial late effects, c) *intervention* for consequences of cancer and its treatment, and d) *coordination* between specialists and primary care providers to ensure all of the survivors' health needs are met (Hewitt et al., 2006).

Adding to this already complex terrain of high quality care recommendations, the CPAC has more recently laid out Pan-Canadian guidelines on the organization and structure of survivorship services (Howell et al., 2011), attempting to adapt the IOM (2006) recommendations for a Canadian context within an evidence-based framework. Tumor site specific guidelines are also now beginning to follow suit (cf. Luctkar-Flude, Aiken, McColl, & Tranmer, 2015). The identified recommendations from these documents include access to survivorship services that

meet a broad range of needs, support for the transition to extended survival, use of a treatment summary and follow up plan, employment of care models and coordination of survivorship services, regular screening for distress and evidence based practice, support for active engagement of survivors in self-management, survivorship education for health care providers, promotion of survivorship issues, leadership in research, evaluation of services, inclusive health policy. Within each of these recommendations, evidence-informed principles and strategies to achieve quality care are outlined (Howell et al., 2011). While these recommendations are somewhat similar to those identified in the IOM (2006) report, the Canadian guideline and recommendations falls short of providing *explicit* direction to consider the influence of structural factors that may promote disparities in survivorship care. Strategies are needed to operationalize these recommendations in ways that consider the interplay of political, economic, social, personal and other factors that influence equitable, high quality survivorship care.

2.4.2 Models of survivorship care. With these quality characteristics, recommendations and essential elements laid out to guide service delivery structure and content, a number of survivorship models of care have evolved over the last ten years including: nurse-led, primary care-provider led, specialist/oncologist-led, shared care, consultative, disease-site, and survivorship clinic models (see for example, Howell et al., 2012; McCabe & Jacobs, 2012; Oeffinger & McCabe, 2006) (see Table 3). These models have been variably implemented and evaluated in North America, with only a beginning understanding of which models are effective for which populations of survivors, to address all or some needs, at what point in their survivorship experience, and in what kinds of settings/organizations (Howell et al., 2012). Further, there may be additional models or approaches to care not yet evaluated within the survivorship population that might also be helpful in achieving equitable high quality care (e.g.,

pediatric cancer survivorship models, chronic illness models, palliative approaches, complementary and integrative medicine (CIM) approaches to care).

I include a critical review of two important reviews of the current state of empirical evidence and knowledge about survivorship models here. The first is a systematic review by Howell et al. (2012) and the second is a report commissioned by the Canadian Association of Provincial Cancer Agencies (2010). Together they provide important foundations and perspectives that will direct future development of Canadian survivorship models of care.

In a systematic review and quality appraisal of the health literature regarding optimal structures of adult survivorship services and models of follow up care, Howell et al. (2012) identified 10 practice guidelines and nine randomized controlled trials (RCTs) for evaluation. This review offered the most current critical review of the *empirical* evidence available at that time²⁰ and recommendations on moving forward with survivor models of care in the Canadian and North American context.

The practice guidelines reviewed in this systematic review (Howell et al., 2012) stemmed from a wide range of cancer-focused organizations, across community-based, tumor-specific, national and international organizations. The guidelines were developed largely based on expert opinion and consensus and made recommendations about service structure, such as timing of follow up visits with health professionals, who those health professionals should be, what level of training they should have, strategies for communication to minimize redundancy, and in some cases, recommendations about availability of interprofessional teams, including rehabilitation specialists and services (Howell et al., 2012). The common theme among these practice guidelines was

²⁰ A subsequent review of models of cancer survivorship care was published in 2015 by Halpern et al. Reflecting on nine empirical studies, it concluded that there was substantial variation in survivorship care models, that the optimal nature, timing, intensity, format and outcomes of these models were uncertain, and that further research was required.

efficiency, moving the survivor through the cancer care system post primary treatment completion to receive high quality services to address their unmet needs. Quality care indicators such as developing healing relationships, promoting survivors' control and choice, were mostly absent from the language in the summaries and key messages reported within these guidelines. One guideline identified ways in which the delivery of services could promote survivor empowerment as a goal, including providing tools and education on how survivors can obtain information, make decisions, solve problems and communicate more effectively with their health care providers. Challenges to this empowerment approach from a health equity lens are discussed later in this chapter.

The nine RCTs reviewed focused on models of care for post treatment follow-up of breast, prostate, lung and colorectal cancer survivors. The majority of RCTs were evaluated within relatively non-complex populations of post-surgical and adjuvant breast cancer patients, significantly limiting the applicability of the review findings to more complex populations of survivors. Reported outcomes included quality of life, psychological functioning (anxiety, depression, well-being), patient satisfaction, recurrence/survival rates, cost, access to medical care and resource utilization. Overall, the review indicated that nurse-led and primary care physician follow up care was equivalent in detecting recurrence when compared to oncologist-led care. Nurse-led care was deemed to be a viable option for implementation within cancer organizations, with the added responsibility to communicate with primary care physicians who care for the survivor's overarching health care needs (Gates & Krishnasamy, 2009). No empirical evidence was found for shared-care models, although share-care is the most frequently recommended model in clinical guidelines, consensus statements and across the cancer survivorship model of care literature (Malin et al., 2011; McCabe et al., 2013; McCabe & Jacobs, 2012).

This systematic review, while providing some helpful beginning knowledge about the current state of knowledge about optimal models of care in relation to select outcomes, was designed using a reductionist quantitative lens that separated facts from values/context. Understanding the context within which these models of care were enacted and exploring the tensions between the structural forces (e.g. political, historical, economic, social) and agency²¹ (e.g. survivor, family, and health care providers) would add depth and breadth to our understanding of how these models of care may/may not promote person-centered equitable high quality care. In particular, survivors' perspectives, beyond that which can be measured quantitatively through patient satisfaction and quality of life tools, is important knowledge to be captured in determining whether quality indicators such as person-centered care, opportunities for choice and control, and establishment of healing relationships, for example, have been experienced. Thus, a study that will help contextualize these quantitative results about optimal survivorship models of care could augment our capacity to better understand how best to move forward with revising and promoting appropriate uptake of these models.

The second report, commissioned by the Canadian Association of Provincial Cancer Agencies (CAPCA), offers empirical and qualitatively-derived insights into how to optimize quality survivorship care. The CAPCA is an interprofessional organization of provincial and territorial cancer agencies and programs that works to promote the highest quality of care and services to Canadians affected by and/or at risk for cancer. The organization is comprised of key leaders (mostly oncologists) from across these cancer agencies and programs and significantly influences how the national cancer control strategy is operationalized within cancer care settings

²¹ Agency – implies having the capacity to engage in deliberate action, which is influenced by the social context and structures within which individuals are imbedded (Sherwin, 1998).

across the provinces and territories. As such, this organization carries significant political, economic and social power/authority/strength within the Canadian cancer care system.

The CAPCA (2010) report includes a literature review, key informant interviews, and an environmental scan on the current communication practices and processes designed to improve communication between oncologists and primary care providers for the transition in care of cancer survivors. Fifty-nine studies were included, mostly from North America and Europe, focusing on examining the communication gap between oncology specialist care and primary care practitioners (PCPs) regarding survivorship care. Survivorship was defined as “the time of partial or complete transfer of medical responsibility for follow-up care to PCPs after potentially curative treatment” (p. 2). The findings from this review must be interpreted in light of the fact that the studies included only those survivors who have potentially curative disease.

Highlights of the literature review findings (CAPCA, 2010) include a clear discrepancy between oncologist and PCP perspectives on who should deliver which aspects of survivorship care. Oncologists preferred to continue to see survivors post treatment, citing better surveillance and lack of trust in PCP skills and knowledge. Conversely, PCPs felt they had the knowledge and skills to deliver survivorship care, which went beyond disease surveillance to include psychosocial support and “preventative interventions” (Grunfeld & Earle, 2010). A lack of consistent use of survivorship care plans (SCPs), inadequate compensation for PCPs and concerns about survivors’ re-referral into the cancer care system were concerns voiced by PCPs (Grunfeld et al., 1995; Nissen et al., 2007; Papagrigoriadis & Koreli, 2001). Outcomes for both care providers were somewhat similar; serious clinical events were extremely rare in both instances (Grunfeld et al., 2006). Only one study looked at *patient* reported outcomes (quality of life, depression, anxiety, satisfaction), which were similar in both PCP and oncologist driven models (Wattchow et al., 2006). Two studies examined PCP care in comparison to nurse-led care,

demonstrating equivalent satisfaction and quality of life outcomes (Grunfeld 2009; Cox et al., 2008).

A number of models to support the transition from active treatment to survivorship care were described, including a collaborative care model, a shared-care model, a consult model, and a community-based PCP/nurse-led model. Grunfeld (2009) notes that rather than determining a “best practice model”, perhaps models should be adopted on an individual basis to best meet the survivorship needs of the patient. Rather than having the survivor adapt to the model, Grunfeld (2009) recommends the model adapt to the survivor’s needs, which is the essence of person-centered care (CPAC, 2014b).

A number of recommendations to improve survivorship care were reported. These included locating oncology nurses in the primary care system, involving PCPs early in the follow-up care, offering education to PCPs specific to various cancer type follow-up, improving two-way communication between PCPs and oncologists, developing a primary care clinic specifically for survivors (and possibly tumor group specific), using SCPs and involving survivors in the development of survivorship plans, and suggesting that oncologists recommend that their patients contact their PCP for follow-up care (to instill confidence regarding PCP ability) (CAPCA, 2010).

The CAPCA (2010) included findings from twenty key informants from across Canada who were interviewed to determine their perspectives on the current approach to cancer follow-up and survivorship care; the preferred model of cancer follow-up and survivorship care; and how to bridge the gaps between the current and preferred approaches. Core themes included keeping the status quo, gaps, envisioned status, best practices, influencing factors, assessing needs, resource requirements, partners and roles, and impacts. Many of these themes were addressed in the

literature review in the previous section; only new concepts, ideas, and strategies that were identified in the stakeholder interviews are presented here.

A number of the stakeholders identified a lack of attention to healthy lifestyles and preventive care in the survivorship period, especially when the oncologist was doing the follow-up care. A few stakeholders recounted the high levels of evidence for exercise and diet and the effect in reducing cancer recurrence, which needs to be incorporated into planning health promotion and lifestyle interventions support to patients (CAPCA, 2010). However, the dialogue within the interviews was centered around the debate, “Oncologist versus physician: Who is best to provide survivorship care?”

Overall, the stakeholder interviews pointed to a shared care or collaborative model for survivorship care based in the primary care system for most survivors. While oncologists have strengths in disease surveillance, PCPs generally have strengths in family and patient-centered care that includes psychosocial and health promotion support. Mention was made regarding the potentially important role of oncology nurses as care coordinators, located within the primary care setting, who could bridge the gap between oncology treatment and primary care systems. The survivor and family perspective was entirely absent in the report. Underserved survivor populations were not discussed, albeit for one comment about lack of access to care for Aboriginal groups. Survivorship care plans, clinical practice guidelines, electronic records, telehealth, and other technologies were identified as tools to enhance communication between oncologists and PCPs (CAPCA, 2010).

This CAPCA (2010) report identified strengths and limitations related to the roles of oncologist and primary care physician in the follow up care of people who have received curative cancer treatment for their cancer. Minimal mention is made of other health care provider roles; when mentioned, these roles mainly focused on how to best support physician practice rather than

meeting survivor needs. One exception was the identification of the need to have nurses based in the primary care system to support the coordination of care, including engagement in health promotion/disease prevention strategies with survivors. It is interesting to note that no mention was made of the *Infermiere Pivot Oncologie (IPO)* nurse model that is based in the primary care system in Quebec. This is a significant gap in this CAPCA report as this IPO model has been rolled out provincially and contextualized to various regions and settings in Quebec; it has also been tested in terms of system and patient outcomes (Fillion, 2011; Fillion et al., 2012; Strutkowski et al., 2008; Strutkowski et al., 2011). There is likely much to be learned by evaluating the strengths and limitations of this model for other provinces, as well as other models of professional oncology nurse “navigation” that are being tested across Canada. Although “navigation” is not without its challenges in terms of its potential to further fragment care across care providers and promote disparities, there are also significant benefits to be examined, such as improved continuity of care, access to care, and other benefits (BCCA, 2005; Pedersen & Hack, 2010, 2012; Pratt-Chapman et al., 2011).

No discussion about how survivors may (prefer to) have primary care providers outside of the western biomedical health care system was included in this review. In British Columbia, increasing numbers of residents are choosing naturopaths and traditional Chinese medicine doctors to act as their primary health care provider after cancer treatment (Murdoch, Hyde-Lay, & Caulfield, 2011). Health promotion and wellness are key foci of care for these health care providers, who may be important adjuncts to support diet, exercise and lifestyle modifications to promote wellness and reduce recurrence risk.

Although the literature review does include a short section on survivor perspectives, this was limited to survivors’ perspectives on the role of PCPs and oncologists in relation to their survivorship care. Any discussion of identifying survivors’ needs, from survivors’ perspectives

was completely absent from this review. Also, there was no mention of the family as the focus of care within the literature review. Without clear identification of survivor/family needs, and a sense of which needs survivors/families want help with (and by whom), it is perplexing how any model of care that aims to be patient-centered and needs focused can be evaluated in terms of effectiveness and satisfaction.

Throughout this CAPCA (2010) report, SCP's were mentioned frequently as an important solution to improve communication. However, only one study and one key informant mentioned the role of the survivor in contributing to the SCP. Although there is mention of using these SCPs to promote patient-centered care, it is unlikely that patient centered care can be achieved without the survivor's input. "Patient-held" care plans were framed as tools for survivors to understand what was expected of them in terms of test and appointments, rather than a plan into which they had input to achieve quality of life as they define it. Without survivor input, any plans for health promotion and/or lifestyle intervention may not be taken up and embraced by the survivor. An emerging body of evidence demonstrates the critical importance of engaging the patient/family in developing the plan for change to optimally support survivors and families to make diet, exercise and lifestyle changes (Demark-Wahnefried et al., 2005; Courneya & Friedenreich, 2011).

Despite holding a vision for improving the transition from active treatment to primary care for survivors, the report largely neglects the survivors' voice. In fact, one statement suggests that it's the survivors' role "to keep the flow of information going and trying to keep the treatment and physicians on track" (p. 30). Exploring survivors' perspectives regarding their experience of receiving patient-centred care in the transition to survivorship care and beyond may help to offer context and an additional angle of view on the necessary elements to achieve equitable high quality survivorship care.

This review of the literature on survivorship models of care reveals a number of gaps and inconsistencies and points to concerns regarding the influence of political, economic, historical, and other factors on the future development of equitable high quality survivorship care. Two key literature reviews on models of survivorship care, developed explicitly to give direction to the development of cancer survivorship models of care and services in Canada, do not consider contextual and other critical factors that are essential to equitable high quality survivorship care. To effectively develop survivorship care that fully considers survivors' perspectives, additional knowledge is essential to complement the empirical evidence generated through these two foundational literature reviews. Further I believe there needs to be a better understanding of the possible influence of political, economic, social, personal and other structural factors on the ability of survivors to enact their agency to achieve quality of life and wellness in the survivorship period.

2.4.2 Survivor perspectives. An essential element of high quality patient-centred care is the inclusion of survivors' voices in determining the goals, process and context of care that is meaningful to them (Arora, 2009; Feuerstein, 2009; Hewitt et al., 2006; IOM, 2001; O'Connor, 2011). As such, one could logically expect survivor perspectives to be held front and center in any dialogue and decision making about survivorship models of care. A review of the literature revealed very few studies describing survivors' perspectives relative to those of health care providers. Most of these studies invited survivors to offer perspectives on existing models of care, whether they prefer oncologist or primary care physician-led care, and the value of survivorship care plans or other interventions such as exercise counseling, using survey methodology (Aubin et al., 2011; Belanger, Plotnikoff, Clark & Courneya, 2011; Cheung, Neville, Cameron, Cook & Earle, 2009; Mayer et al., 2012; Sisler et al., 2012) and focus groups (Hewitt et al., 2007; Kantsiper et al., 2009; Smith et al., 2010; Urquhart, Folkes, Babineau & Grunfeld, 2012).

Two studies used inductive approaches to explore survivors' perspectives at the transition from primary treatment to survivorship care (Roundtree, Giordano, Price & Suarez-Almazor, 2011; Thorne & Stajduhar, 2012). One study used a community participatory action approach to explore the acceptability of survivorship care plans in a community of black American breast cancer survivors (Ashing-Giwa et al., 2013).

A number of narratives have reported on various survivors' experiences of engaging with the survivorship care system (Arora, 2009; de Guzman et al., 2013; Ehrenreich, 2001; Feuerstein, 2009; King, 2006), which is helpful to orient toward aspects of care that require further exploration in future research. Almost completely missing in the literature are the voices of underserved and marginalized survivor groups, making designing models of care that are equitable and inclusive an impossibility (Ashing-Giwa et al., 2013; Brooks, 2010; de Guzman et al., 2013). People experiencing marginalizing conditions within society rarely are included in research, nor are their perspectives commonly sought to inform health care policies and systems (Anderson, et al., 2003; Anderson et al., 2009).

Across these studies on survivor perspectives regarding their experience of current survivorship care, the main themes include:

1. Transitions from primary treatment to survivorship care are stressful and require guidance and support from health professionals.
2. How health professionals communicate with each other and survivors shapes and influences the experience of this transition and beyond.
3. Effective communication between oncologists and PCPs regarding the treatment summary and required follow up care is lacking.
4. Being actively engaged in decisions about care is helpful for survivors as long as appropriate support from health professionals is provided.

5. Practicing health promotion behaviors (e.g. diet, exercise, weight maintenance) is difficult and requires ongoing support and coaching from health professionals to contextualize to the survivors' unique needs.
6. Support for contextualizing and practicing health promotion activities is largely missing from the current model of survivorship care (Arora, 2009; Aubin et al., 2011; Belanger et al., 2011; Cheung et al., 2009; de Guzman et al., 2013; Feuerstein, 2009; Hewitt et al., 2007; Kantsiper et al., 2009; Mayer et al., 2012; Roundtree et al., 2011; Sisler et al., 2012; Smith et al., 2011; Thorne & Stajduhar, 2012; Urquhart et al., 2012).

Other recommendations included: building opportunities into survivorship care structures to develop relationships to foster communication and contextualize care to the survivor's unique situation, providing anticipatory guidance for transitions, acknowledging and addressing the anxieties inherent in living as a cancer survivor, and providing ongoing coaching and support for health promotion lifestyle changes (Belanger et al., 2011; Thorne & Stajduhar, 2012).

Although PCPs (physicians and nurse practitioners) were generally regarded as acceptable to deliver ongoing survivorship care, survivors felt PCPs required more disease-specific knowledge and should be involved in their care during treatment to facilitate confidence and trust in their PCP, and transitions to survivorship (Aubin et al., 2011; Mao et al., 2009; Sisler et al., 2012; Urquhart et al., 2012). In-person versus virtual visits were seen as favorable, although this perspective was based on a sample of white female breast cancer survivors of high socioeconomic status who were able to travel to a cancer/health care centre (Mayer et al., 2012). Survivorship care plans were seen as important to communicate treatment plans and the need for recommended screening but were seen as insufficient as a communication strategy on their own (Mayer, 2014). Survivors recommended being involved in the development of the survivorship

care plan, so that it could be individualized to their own unique needs and inclusive of their beliefs, values and goals (Ashing-Giwa et al., 2013; Kantsiper et al., 2009; Smith et al., 2011).

This body of knowledge on survivors' perspectives offers a beginning understanding of how to best evolve current care models to achieve high quality survivorship care. However, opportunities have not been created for survivors to voice their perspectives on innovative ideas and priorities for an envisioned future system of care that promotes equity and high quality survivorship care.

2.4.3 Non-cancer models and approaches. As cancer has become a chronic illness with complex care needs well beyond the end of primary treatment, a review of other pediatric and non-cancer models and approaches to care may be helpful to expose key aspects of care delivery that may be helpful within an adult cancer survivorship context. Although it is outside of the scope of this literature review to engage in a full review of all pediatric and non-cancer models and approaches to care, a few select models and approaches are briefly summarized here to offer additional insights and cautions that may be useful in moving forward the cancer survivorship care agenda. Pediatric oncology survivorship care models, general chronic illness models, palliative approaches to chronic illness care and approaches to integrating complementary and integrative medicine are explored here.

2.4.3.1 Pediatric cancer survivorship models. Although the needs of adult and pediatric oncology survivors are somewhat similar, formal survivorship programs and services are more likely to be in place for survivors of pediatric cancer than for those diagnosed with cancer as adults (Landier, 2007; Oeffinger, Hudson & Landier, 2009). This increase in availability of resources for pediatric survivorship care may be associated with the establishment of pediatric cancer long-term follow up guidelines in the US (Bowers et al., 2009; Children's Oncology Group (COG), 2007). With the establishment of clinical practice guidelines, recommended care

can be reimbursed and access to recommended services increased (Armenian et al., 2013). It may be that, the publication of adult survivorship follow-up guidelines in Canada (Howell et al., 2011), will have influenced a similar growth in the availability of recommended services and resources. However, social, political and economic factors such as, for example, establishing reimbursement policies, availability of skilled oncology health professionals to deliver survivorship care and use of communication strategies such as survivorship care plans likely will play a role in enabling or minimizing the uptake of the guidelines in practice. Exploration of these contextual and structural factors will be helpful to anticipate how to best to use/position these guidelines to facilitate equitable high quality survivorship care.

As with adult cancer survivorship, there is great variability in the types of pediatric survivorship models of care available, with no one “best model” advocated (Landier & Bhatia, 2008; MacDonald, Fryer, McBride, Rogers, Pritchard, 2011; McBride et al., 2011; McCarthy, Campo & Drew, 2013; Oeffinger, Hudson & Landier, 2009). In Canada, large cancer centres where pediatric oncology survivorship expertise is available, survivorship (also known as “after care” or “late effects”) clinics have begun to be established (see for example, Pediatric Oncology Group of Ontario Aftercare Program, 2014). These clinics vary in scope and range from being led by an expert oncology nurse or oncologist to including an interprofessional care team to address the physical, psychological, educational, sexual, financial and other needs associated with the survivorship phase. In rural settings, where this oncology health professional expertise is not available, follow up care is delivered by primary care providers, with referral back to specialist care as needed. Across these models, the COG clinical guidelines are used to direct care (Eshelman-Kent et al., 2011).

2.4.3.2 Chronic illness models. Chronic illness models of care, such as the Chronic Care Model (CCM, Wagner 1990) or the expanded CCM (Barr et al., 2002), may offer opportunities to

integrate cancer survivorship care into primary care. As many survivors, particularly those who are older, may have co-morbid chronic health conditions (e.g. diabetes, hypertension, arthritis), they may already be receiving care within a chronic care model for that condition (Yu, 2011). Pragmatically it makes sense not to further fragment care for these individuals and to look for opportunities to include cancer survivorship care within chronic illness models. Also, opportunities to build cancer survivorship care as an integrated component of existing chronic illness models could help policy-makers in operationalize the essential elements for quality survivorship care into practice (Feuerstein & Ganz, 2011).

The expanded CCM model (Barr, 2002) includes positive components such as the availability of a multidisciplinary team and an engaged supportive community to reduce some of the structural barriers facing survivors. However, a key tenet of the model is self-management, which has been demonstrated to promote inequities and place undue burden on individuals when their agency is constrained due to structural factors out of their control (Thorne, 2008a).

Research on the feasibility and success of chronic care models shows some limitations. Out of 100 studies on chronic illness management programs, only one implemented all six elements, and the self-management/behavior change management element was the least commonly implemented (Tsai, Morton, Mangione & Keeler, 2005). Patient education was the most frequently implemented element, followed by multidisciplinary team decision making regarding care. As the number of elements in a program increased, outcomes (e.g. quality of life) improved (Hung, et al., 2008; Tsai, 2005). No studies could be located that evaluate the integration of cancer survivorship care into a chronic illness model.

2.4.3.3 Palliative approaches to chronic illness care. A somewhat related but significantly different approach to addressing chronic illness involves a *palliative approach* to care. Stepping away from a focus on prognosis, a palliative approach applies principles of palliative care to

engage with patients and families about their needs, values and goals for care; provide information and decision support; offer support for psychosocial, spiritual and cultural issues; and interventions to promote quality of life (Coventry, Grande, Richards & Todd, 2005; Jackson, Mooney & Campbell, 2009). Early identification of physical, psychosocial, spiritual and other concerns is a key tenet of a palliative approach, which can be applied to any individual regardless of their illness type or stage (Katz & Pierce, 2003; Kristjanson, 2005; Kristjanson, Toye & Dawson, 2003). Life-prolonging and curative treatments may be delivered alongside of supportive care therapies to promote quality of life (Kelley & Meier, 2010).

A palliative approach to care begins at the time of diagnosis and continues through until the end of life and is not bound to any particular care setting (Stajduhar, 2011). While specialist teams may be needed to address complex patient needs, a palliative approach to care may be delivered by any health care professional who cares for individuals experiencing life-threatening illness (Shadd et al., 2013). Palliative approaches to care have been implemented across numerous disease types (e.g. neurodegenerative disorders, elder care) and care settings (e.g. long-term care, rural settings, primary care) (Kristjanson et al., 2003; Pesut, McLeod, Hole & Dalhusen, 2012; Shadd et al., 2013; Toye et al., 2012).

Applied to the cancer survivorship population, the palliative approach to care offers possibilities for delivering equitable, high quality survivorship care. By removing the *singular* focus on cancer and recurrence prevention, the palliative approach is inclusive of a more holistic and wellness focused approach to survivorship care that considers disease surveillance while at the same time better aligning with person-centred care (CPAC, 2014b, 2014c). Access to survivorship care would be enhanced, as all health care providers who care for cancer survivors (e.g. primary care physicians, nurse practitioners, oncology and generalist nurses) would offer basic survivorship care, beginning at the time of diagnosis. Complex survivor needs would be

addressed by specialist oncology health care professionals (e.g. oncologist, oncology nurses) working in interprofessional teams. Health care provider education, policies and communication strategies across care settings are among the multitude of structural supports that are needed to enact a palliative approach to survivorship care.

2.4.3.4 Complementary and integrative medicine (CIM) approaches. Similar to a palliative approach to care, a CIM approach puts patients/families in the centre and brings the best of both complementary and conventional care together to address what is most important to those individuals. Care is tailored according to patient/family beliefs, values and goals, with an end in view of optimal health and well-being, regardless of disease state. Practice is based on empirical evidence and a variety of sources of knowledge (e.g. historical, experiential) to address psychological, social, physical, spiritual, and other needs. Health promotion and disease prevention are significant foci within a CIM approach, although managing the sequelae of living with complex chronic health conditions is also commonly addressed. A CIM approach to care involves a partnership between the patient/family and a multidisciplinary team of health care providers (e.g. physician, naturopath, massage therapist, dietician) to ensure there is good alignment between the patient's voiced needs and appropriate health care resource (Maizes, Rakel & Niemiec 2009; Mulkins, Eng, & Verhoef, 2005). Although care for each patient and family within a CIM approach is individualized and generally delivered one-on-one within a private payment system, innovative strategies are being tested in Canada to individualize care within group medical visits (covered by some provincial medical plans), increasing access and reducing costs for those seeking a CIM approach to care (see for example, Connect Health, 2014).

A CIM approach offers opportunities to tailor care to effectively address health promotion and lifestyle modification aspects that are currently significant gaps in cancer survivorship care (Casillas & Ayanian, 2011; Weaver, Rowland, Bellizzi, & Aziz, 2010). Further, this approach

reduces care fragmentation and silo-ing of care providers, which has the potential to reduce patient satisfaction and quality of care outcomes (Reimer Kirkham & Browne, 2006). A CIM approach to care is particularly valuable when co-morbidities are involved, as the interprofessional team assembles around the survivor, rather than dividing survivors up into their various disease components and sent off to various specialists to have their needs addressed (Edgington & Morgan, 2011).

Significant challenges exist to enacting a CIM approach to care for the survivor population in the current health care system. Some examples of these challenges include biomedical paradigm dominance within the cancer and survivorship care system, incommensurable ontologies and epistemologies between CIM and biomedical sources of knowledge, general mistrust between conventional oncology health care providers and CIM practitioners, and a general lack of inclusion of CIM practitioners and therapies within the fee reimbursement system (Adams, Hollenberg, Lui & Broom, 2009; Broom and Tovey, 2007a, 2007b; Hollenberg & Muzzin, 2010; Keshet, 2009; Parker, 2007). However, as the rapidly growing body of empirical evidence surrounding CIM continues to increase, and survivor advocacy groups make their collective voice regarding the need and desire for a CIM approach heard by decision makers, the acceptability and possibility for introducing a CIM approach to care for cancer survivors becomes greater. To ensure equity and prevent further marginalization of those without means to pay for CIM therapies, strategies to place efficacious CIM therapies within the medical services plan will also need to be undertaken.

2.4.4 Health equity strategies. With equity a concern across most health care systems in Canada and abroad, (Commission on Social Determinants of Health, WHO, 2008; Health Council of Canada, 2013; WHO, 2007) useful strategies employed to promote equity in other settings and health systems may offer some directions for cancer survivorship care. A review of research on

health equity strategies enacted across a variety of settings and systems at local, national and international levels (i.e. primary care organizations) revealed a common set of themes:

1. The quality of care at the individual or community level is shaped by policies at the local, regional and national level. Influencing policy is an essential aspect of quality, equitable care (Kelly, 2009; Moy et al., 2011; Raphael, 2010).
2. Interventions to address the social determinants of health should be a routine aspect of health care, often as a main priority (Browne et al., 2012; Raphael, 2010; Tamburlini, 2004).
3. Culturally and linguistically competent care is essential to deliver patient centered care that takes into consideration cultural meanings of health and illness, as well as effects of racialization, discrimination and marginalization (Browne et al., 2012; Printz, 2012).
4. Provider communication can influence disparities in terms of content and time to develop relationships (Browne et al., 2012; Mack, Paulk, Viswanath & Prigerson, 2010; Printz, 2012).
5. Reinforcement is needed about the centrality of patient-centered care, tailoring care, programs and services to the context of people's lives (Browne et al., 2012)
6. Community-based, collaborative and participatory engagement approaches are essential (Browne, 2012; Ramanadhan et al., 2012)
7. Navigation can be an effective strategy to improve coordination of care (Campbell, Craig, Eggert & Baily-Dorton, 2010; Esparza & Calhoun, 2011)
8. The primary care setting is more effective than specialty care (as it is currently configured) in addressing the social determinants of health and promoting health (Starfield, 2009; Starfield, Shi & Macinko, 2005)

These themes reflect the importance of considering both an individual and community/population perspective and approach to promoting equity in health care settings and systems. Much of the dialogue within the cancer survivorship literature focuses on models of care and resources for individuals. However, these aforementioned themes applied to a cancer survivorship context will necessitate a broader perspective that also considers the health of a community or population to sustain long-term impacts on modifying the social determinants of health. Browne et al. (2012) suggests that the concept of patient-centered care be expanded to include *contextually-textured* care, where services are tailored specifically for the communities served. An example in the cancer survivorship context might include offering a co-led (survivor and trainer with cancer expertise) exercise walking exercise program for new immigrant women survivors, in their preferred language, with childcare available. This program could be based on partnership with a local community center or place of worship and could be developed based on engagement with this community to determine their specific interests and needs. From a primary care lens, organizing and sustaining a model of care that is inclusive of these types of services and programs at a community or population-based level, can be challenging. However, opportunities to enact these types of contextually based care groups have grown over the last decade. For example, the concept of group “medical” visits²² is an approach that has become more prevalent, due in part to remuneration within the Medical Services Plan in British Columbia (British Columbia Ministry of Health, 2014). These group medical visits bring together individuals with a common health concern or chronic illness to receive one-on-one medical assessment, education within a framework of social support in a group setting (Edelman, 2012;

²² Group medical visits may also be called Shared Medical Appointments, Shared Care Visits, Drop-in Group Medical Appointments. A variety of health professionals, such as nurses, nurse practitioners, physicians, social workers, physical therapists, psychologists, etc. may lead/co-lead the group, depending on the nature of the group, regulatory policies, and reimbursement structures within the setting (Trotter, 2013).

Martin et al., 2004; Trotter, 2013; Trotter, Frazier, Hendricks & Scarsella, 2011). These models have demonstrated improved health outcomes in diverse populations of patients with diabetes (see for example, Housden, Wong & Dawes, 2013), asthma (see for example, Rhee, Cieurzynski & Yoos, 2008), pre and postnatal care (see for example, Ickovics et al., 2007), arthritis (see for example, Shojania & Ratzlaff, 2010), chronically ill older adults (see for example, Levine, Ross, Balderson & Phelan, 2010), and hypertension and heart failure (see for example, Brannon, Ellis, & Southall, 2010; Yehle, Sands, Rhynders & Newton, 2009). Group models have also demonstrated benefit in vulnerable groups such as those living in rural communities, low income, or uninsured (see for example, Mallow, Theeke, Whetsel & Barnes, 2013).

Group cancer survivorship visits have recently been implemented in the US, with improvement in outcomes such as acceptability, participation rates, ability to follow their survivorship care plan, and perceptions that their needs were met (Trotter et al., 2011). Additional benefits such as mutual social support, information sharing, support to manage self-care strategies, increased sense of trust and perceptions of receiving individualized care within these group visits also have been described (Lavoie et al, 2013; Trotter, 2013). Although group visits will not meet the needs of all survivors (e.g. those with complex needs, those for whom a group setting is not desirable or feasible), there is potential to address basic needs within select survivor groups/populations.

2.5 Survivor Health Management Strategies and Lifestyle Behaviors

Against a backdrop of fragmented health care systems and variable models of survivorship care, many survivors employ their own strategies and practices to address their unmet needs for symptom management, health promotion and recurrence prevention (Becker & Kang, 2012; Bellizi, Rowland, Jeffery, & McNeel, 2005; Harding, 2012; Hawkins et al., 2010; Karvinen, Murray, Arastu & Allison, 2013; Mao et al., 2011; Mao et al., 2008; Mayer et al., 2007;

Meraviglia & Stuijbergen, 2011). Some of these strategies may be sanctioned and encouraged within the conventional health care system (e.g. diet, exercise, smoking cessation, sleep hygiene), and others practiced within the complementary health care system (e.g. acupuncture, naturopathy), often without the knowledge or support of conventional health care providers (Balneaves, Weeks & Seely, 2008; Davis, Oh, Butow, Mullan, & Clarke, 2012; Mao et al., 2011). A discussion of these practices and strategies offers insights into how to evolve safe, equitable, high quality survivorship models of care to be more patient-centered and sensitive to the unique needs and values of survivors.

2.6 Health Promotion and Cancer Survivorship

Since the early 2000's, a mounting body of evidence has demonstrated that health promotion and lifestyle behaviors (e.g., exercise, nutrition/diet, weight maintenance, smoking cessation, sun safety) do play a role in survivors' quality, disease-free survival and length of life (Brunet, Sabiston, & Meterissian, 2012; Campbell, Stevinson, & Crank, 2012; Courneya & Friedenreich, 2011; Davies, Batehup & Thomas, 2011; Ligibel, 2012; Loprinzi & Lee, 2014; Kushi et al., 2012; McNeely et al., 2006; Milne, Gordon, Guilfoyle, Wallman, & Courneya, 2007; Pollard, Eakin, Vardy & Hawkes, 2009). A landmark report offering a global metasynthesis of lifestyle research evidence and providing recommendations on food, nutrition, and physical activity and cancer prevention, also makes an additional special recommendation that cancer survivors should also follow these recommendations for cancer prevention (World Cancer Research Fund/American Institute for Cancer Research (WCRF/AICR), 2007).²³ American consensus guidelines regarding

²³ The WCRF/AICR (2007) cancer prevention recommendations for cancer survivors include: 1) Be as lean as possible without becoming underweight, 2) Be physically active as a part of everyday life, 3) Limit consumption of energy-dense foods, 4) Eat foods mostly of plant origin, 5) Limit intake of red meat and processed meats, 6) Limit alcoholic drinks, 7) Limit consumption of salt and moldy grains/legumes, and 8) Aim to meet nutritional needs through dietary sources alone (no supplements).

exercise specifically for cancer survivors have been established, offering an overarching “exercise prescription” with modifications specific to each cancer type (Schmitz et al., 2011).

Research illustrates, however, that few survivors are able to meet these lifestyle recommendations for health promotion (Hyland, Lennes, Pirl, Smith & Park, 2014; Mayer et al., 2007; Neil et al., 2014; Osborn, Psota, Sa & Sbrocco, 2011). In one large population-based study, more than half of American cancer survivors were inactive and 58% were overweight or obese (BMI>25%), and neither cancer survivors nor non-cancer controls obtained sufficient physical activity (Mayer et al., 2007). A recent large Canadian study by Neil and colleagues (2014) demonstrated similar findings where those currently with cancer, those who reported having had cancer in the past, and those never having cancer, all reported activity levels lower than recommended.

Disparities in survivors’ health behaviors are reported in a number of studies, demonstrating more unfavorable health behaviors among cancer survivors who were younger, female, identified as lesbian or bisexual, identified as non-white racial/ethnic backgrounds, had lower socioeconomic status and lived in a rural versus urban setting, when compared to their non-cancer counterparts. (Boehmer, Miao & Ozonoff, 2012; Hawkins et al., 2010; Meraviglia & Stuijbergen, 2011; Rausch et al., 2012; Weaver, Palmer, Lu, Douglas & Geiger, 2013b; White et al., 2013). These disparities have been attributed to structural, social, and environmental factors such as lack of access to lifestyle information and ongoing support contextualized to individuals’ unique needs, beliefs, goals and language; lack of family involvement in educating and supporting the lifestyle behaviors; lack of health insurance to pay for prevention services or funds for other health promotion costs (e.g. quality food, access to exercise facilities) and lack of practical support such as child care and transportation (Casillas & Ayanian, 2011; Weaver, Rowland, Bellizzi, & Aziz, 2010).

Some have suggested that a cancer diagnosis is a “teachable moment” and a catalyst for making positive lifestyle and behavior changes (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Demark- Wahnefried et al., 2000). However, based on the aforementioned studies citing lack of healthy behaviors reported among the cancer survivor population, simply providing teaching about evidence-based healthy behaviors at the “right time” seems to be largely ineffective in achieving the practice of healthy behaviors by survivors. A more recent study testing this “teachable moment” concept regarding physical activity in early the breast cancer survivorship trajectory reinforces the notion that motivating and sustaining behavior change is complex (Broderick, Hussey, Kenney & O’Donnell, 2014).

While the majority of these health behavior studies identify various individual factors that promote disparities in health promotion behaviors and could be a target of intervention for evolving survivorship models of care, it is unlikely that any one of these factors alone account for the disparities experienced by any one individual. People are complex beings and may experience a number of factors in combination to promote disparities that impact survivors’ ability to practice health-promoting behaviors. Further investigation of how these factors layer and intersect in survivors’ lives to promote disparities warrants exploration. Also, exploring helpful and unhelpful practices and strategies with survivors to minimize these “bundled” and intersecting factors which promote disparities will also be useful knowledge to support the practice health behaviors that meet the evidence-based recommendations in a way that is meaningful and sustainable for these individuals.

The use of Complementary and Integrative Medicine (CIM)²⁴ therapies and practices by survivors to address their wellness and health promotion needs is also growing. Up to 80% of

²⁴ CIM – A group of diverse medical and health care systems, practices, and products not presently considered to be a part of conventional biomedicine and are used *in addition to* conventional biomedicine

survivors use CIM, yet most do not discuss their use with their health care providers, leading to concerns about safety and missed benefits for those therapies for which positive evidence exists (Balneaves, Weeks, & Seely, 2008; Mao et al., 2011; Mao et al., 2008). Reasons for CIM use among survivors are varied, including decreasing risk of recurrence, enhancing well-being, addressing symptoms not well managed by biomedicine, increasing hope and control, better alignment with personal belief systems and cultural health practices, and to a lesser extent, dissatisfaction with biomedicine (Balneaves, Weeks, & Seely, 2008; Bell, R. M., 2010; Gansler, Kaw, Cammer & Smith, 2008; Mao et al., 2011; Mao et al., 2008). In one population-based study, Mao et al. (2008) found that cancer survivors with unmet needs were more likely to use CIM than those who had their needs adequately addressed. For many survivors, CIM was a part of their health practices before being diagnosed with cancer, and continuing these practices helped them to ease the transition post treatment and feel like they are “getting back to normal”. Numerous challenges exist for survivors to integrate their CIM use into their survivorship plans of care. Examples of these challenges include: A lack of knowledge about CIM by oncology health professionals, location of care within a biomedically-driven health care system that privileges EBM-driven knowledge over other forms of knowledge, and a lack of insurance/funding for many CIM therapies used for health promotion by survivors (Boon et al., 2000; Cassileth, Heitzerv & Gubili, 2008; Esrnst & Cassileth, 1998; Huntley, de Valois, Dog & Borrelli, 2012; Mao et al., 2011). A growing body of evidence as well as clinical practice guidelines to guide evidence-informed decision making about the integration of CIM into survivorship care offers opportunities to be inclusive of CIM within survivorship models of care

(NCCAM, 2008). Five categories of CIM therapies are identified, including mind-body (e.g. meditation), body-based (e.g. chiropractic), energy-based (e.g. acupuncture, Reiki), biologic (e.g. natural health products), and whole medical systems (e.g. Naturopathy, Traditional Chinese medicine, Ayurvedic medicine).

for those who deem this important and meaningful to their care (Deng et al., 2009). However, considerations must be made regarding equity of CIM services as currently most therapies are not funded within the conventional health care system, which seems something of a contravention of the Canada Health Act (1984) which positions itself to promote equity in access of health services to protect, promote and restore the physical and mental well-being of all Canadians (Government of Canada, 1984).

It is clear that there exists a gap between the evidence indicating that health and lifestyle behaviors will reduce risk of recurrence and promote quality of life (e.g. diet, exercise, weight maintenance) and the agency of survivors to enact these behaviors after the completion of primary cancer treatment. Missing from the literature are survivors' perspectives on what strategies would be helpful to practice these health and lifestyle behaviors and how these strategies may be contextualized to meet their unique needs, beliefs, values and goals for health and wellness. An exploration of the strategies required at the individual and community/population level, paying attention to the interplay of agency and structure, also will be useful in designing future survivorship care models and resources that promote equitable, high quality survivorship care.

2.7 Metanarratives and Ideologies Influencing Cancer Survivorship Care

Taking a slightly different approach and angle of vision, in this final section of the review of the literature I critically explore metanarratives²⁵ and ideologies influencing equitable, high quality cancer survivorship care. Beginning with exploration of survivorship itself as a metanarrative, I uncover complexities such as the mismatch between societal expectations and many survivors' experiences of surviving cancer, and the implications of self-care ideologies.

²⁵ Metanarrative – a term often used interchangeably with dominant discourse. It is a system of words, actions, rules, beliefs and institutions that share common values, created by those in power (Crotty, 1998).

Biomedicine, the dominant discourse shaping cancer treatment and survivorship care also poses challenges to enacting equitable high quality care. Using a critical approach, I deconstruct and analyze ideologies imbedded within biomedicine including corporatization of health care, neoliberalism and dividing practices embedded within specialization. Through this deconstruction I aim to expose and explore the tensions created by these metanarratives and ideologies, making inconsistencies apparent (Derrida, 1974; Dzurec, 2003; Reed, 2009; Rolfe, 2005). As a result of barriers imposed by these metanarratives and ideologies, I argue that knowledge available to inform high quality survivorship care is impeded and health inequities are unwittingly promoted.

2.7.1 Survivorship as a metanarrative. Further complicating the complex terrain upon which definitions of cancer survivorship are situated, organizations that aim to improve the length and quality of life of survivors, such as the pharmaceutical industry, cancer advocacy groups, and the biomedically-driven cancer treatment system, have influenced both survivor definitions and societal expectations of survivor behavior (Batt, 1994; Bell, K. 2010, 2012; Bell & Ristovski-Slijepcevic, 2012; Ehrenreich, 2001; Sinding & Gray, 2005). Media and marketing campaigns aimed at shaping perceptions of cancer patients who have completed their treatments as survivors winning the battle against cancer and thriving in the face of a significant trauma have contributed to a metanarrative about cancer as a positive transformative process (Batt, 1994; Bell, K. 2010, 2012; Ehrenreich, 2001; King, 2006; Little et al., 2002; Thorne & Murray, 2000). This metanarrative of the cancer survivor as a triumphant hero, resilient, in control, healthy, and with lots of support, while offering an image of hope, creates an illusion that may not be reflective of the actual lived experience of cancer survivorship for many. In fact, for some survivors, this metanarrative further marginalizes their own, and more common, experience. The post-treatment experience may be fraught with late and long-term side effects such as fatigue and depression, unable to return to work with associated financial worries, changes in roles and relationships, and

ongoing fears of recurrence (Campbell et al., 2011; Corner, 2008; Ehrenreich, 2001; Hewitt et al., 2006; Miller, 2012; Saillant, 1990).

The concept of liminality²⁶ has been used to describe this sometimes invisible space post primary treatment completion, where survivors feel they cannot express their own experience or ask for help, for fear of being viewed as a failure when they cannot maintain a positive, heroic, self-managing persona (Blows, Bird, Seymour & Cox, 2012). The metanarrative of the triumphant cancer survivor may inadvertently put many survivors on the margins of everyday life, where they find themselves, “in betwixt and between”, confined to an invisible borderline condition between well and unwell, believing their cancer is gone yet may still recur (Blows et al., 2012). This mismatch between the socially constructed, acceptable image of cancer survivorship and the actual/lived experience of cancer survivorship magnifies the ambiguity experienced by many cancer survivors as they transition from cancer patient to survivor post primary treatment completion (Miller, 2012; Thorne & Stajduhar, 2012).

Embedded within this survivorship metanarrative is the concept of self-care²⁷. Survivorship care encourages and directs many individuals to take on new health behaviors to promote their health and reduce the risk of recurrence. Self-care ideologies²⁸, rooted in neoliberalism, negates the social, political and cultural norms and contexts that shape health, creating an illusion that ill-

²⁶ Liminality is an interstructural situation where culturally recognized positions (e.g. being married, an infant) no longer apply. People in liminal spaces are no longer classified, yet not classified, and are often described as on the margins (Turner, 1969).

²⁷ Self-care involves a range of health care decision making and care undertaken by individuals on their own behalf (Dean & Kickbush, 1995).

²⁸ Ideology is a comprehensive vision, a way of looking at things, as in common sense or a set of ideas proposed by a dominant class of society to all members of society. The main purpose behind an ideology is to offer either a change in society, or adherence to a set of ideals where conformity already exists, through a normative process. It is how society sees things (Blackburn, 2008; Crotty, 1998; Giddens, 1997).

health springs from the characteristics or behaviors of individuals (Dean & Kickbush, 1995). This ideology further constrains individuals' abilities to enact agency, placing responsibility within individuals for choices and actions to restore and preserve health, as well as the outcomes of those actions (Dean & Kickbush, 1995; Foster & Fenlon, 2011). This individualized responsibility for health is observed within survivorship lifestyle discourses related to preventing cancer recurrence (see for example, Pekmezi & Demark-Wahnefried, 2011). Lifestyle interventions, largely promoting self-care strategies, are focused on mediating individuals' behaviors without considering the social, political, economic and other forces shaping health behavior, possibly leading to victim-blaming where, regardless of whether or not individuals have the agency to address the health issue, they are held responsible for their health outcomes. Individuals who experience marginalizing conditions within society (e.g. discrimination due to gender, ethnicity, social class, socio-economic status) are most at risk for victim blaming, further oppressing and promoting health disparities (Anderson, 1996; Anderson et al., 2009; Bell, K., 2010; Mahon, 2007; McLeod & Sherwin, 2000; Northrup, 1993; Sherwin, 1998).

A number of studies, largely with breast cancer survivors, have begun to quantify and *describe* the implications of continuing to reinforce the survivorship metanarrative and self-care ideologies through survivorship care strategies (Bell, K., 2010, 2012; Blows et al., 2012; McKenzie & Crouch, 2004; Ehrenreich, 2001; Kaiser, 2008; Little et al., 2002; Sinding & Gray, 2005). However, no studies could be located that give *direction for action* on how survivorship care could be developed to support survivors to voice their actual needs, rather than portraying the socially constructed image of managing well, or to embrace self-care strategies contextualized to their unique situation without the associated complete responsibility for outcomes of those strategies. Effective survivorship care must consider that there be a mismatch between the socially constructed survivorship metanarrative and one's actual lived experience.

2.7.2 Situating biomedicine. While the application of the biomedical model within cancer care has produced significant numbers of people living longer with a cancer diagnosis, reliance on this Cartesian-reductionist view of the human body as the *only* foundation upon which to base survivorship care poses significant threats to the development of high quality survivorship care (Barry, 2006; Hollenberg & Muzzin, 2010; Kelly, 2009). Within the biomedical paradigm, the mind is seen as separate from the body, health is equated with the absence of disease, and the phenomenon of healing is excluded. Scientific evidence (as per Popper, 1959) upon which cancer treatment is based is largely derived from randomized controlled trials (RCTs) and applied within an evidence-based medicine (EBM) framework (Sackett et al., 1996). Facts are separated from values and traditional forms of knowledge, such as historical or personal knowledge, are seen as irrational and not justifiable (Capra, 1982).

Evidence-based medicine, a significant metanarrative influencing survivorship care, is considered the gold standard for “truth” within biomedicine and espouses a post-positivist ontology²⁹ and epistemology³⁰ (Rolfe, 2005). The acontextual, value-free knowledge developed through EBM serves as a key foundation for survivorship resource development, such as clinical practice guidelines, recommendations for survivor follow up care, including health promotion practices. While these resources may provide direction for care of *populations* of survivors, they cannot inform the care of the infinitely complex *individual* surviving cancer (Thorne & Sawatzky, 2014). To apply this population-based knowledge in everyday practice, evidence must be contextualized through the infusion of other forms of knowledge (e.g. qualitatively derived research findings; personal, intuitive, aesthetic and ethical knowledge as per Carper, 1978)

²⁹ Ontology is concerned with the structure of reality, the nature of existence, the “what is” (Crotty, 1998).

³⁰ Epistemology is the branch of philosophy concerned with the theory of knowledge. “How we come to know what we know” (Crotty, 1998).

(Liaschenko & Fisher, 1999; Purkis & Bjornsdottir, 2006; Thorne & Sawatzky, 2007, 2014).

Qualitative research findings can be “corrective” to empirical research, providing the much-needed context that helps to interpret the meaning and application of this empirical evidence for individuals (Thorne, 2011; Thorne & Sawatzky, 2007, 2014). Consider the example of the middle-aged female lymphoma survivor with arthritis, who at the end of primary treatment is offered evidence-based exercise guidelines to reduce her risk of recurrence and address her ongoing fatigue. The survivor is a single parent with dependent children and cares for her aging mother with dementia in her home. Her resources are limited, she does not have access to a gym, and she is experiencing mild depression, making motivation to exercise a challenge. The exercise guidelines, developed largely based on a cohort of younger breast cancer survivors without other complex diseases, does little to contextualize the exercise recommendations to fit with this survivor’s unique situation. Without ongoing support to manipulate the structures (e.g. resources, time, support, access) that limit her capacity to enact the exercise guidelines, she may experience exercise as one more barrier to overcome in regaining and maintaining her health after treatment.

In a culture that preferences EBM as the singular source of knowledge, “disease-monitoring” is often conflated with “care”. This conflation is reflected in the plethora of tumor-driven clinical practice guidelines that outline recommendations for screening and disease monitoring for cancer survivors. The development of survivorship care plans also reflects this disease focus, with medical treatment summaries and screening guidelines to monitor for disease recurrence taking priority over other measures important for quality care such as support to practice health promotion behaviors or address financial and return to work issues (Mayer, 2014).

A singular reliance on empirical evidence generated through EBM also limits consideration of the integration of complementary forms of health care systems and practices (Avis & Freshwater, 2006; Broom & Tovey, 2007a, 2007b; Goldenberg, 2005; Lambert 2006; Upshur, 2005). With

incommensurate ontologies and epistemologies, the hegemonic influences of EBM and its quest for a singular “truth” supersedes the holistic³¹ underpinnings of CIM where multiple realities may be co-constructed (Broom & Tovey, 2007a, 2007b). With most survivors either using or thinking about using CIM (Mao et al., 2011; Mao et al., 2008), it is imperative that strategies to address this perceived incommensurability be employed so that CIM may be integrated to promote safe, person-centred quality survivorship care.

In addition to the influences of the EBM metanarrative, a number of ideologies associated with biomedicine have shaped the development of survivorship care. Three key ideologies are discussed here, including corporatization, neoliberalism and specialization.

2.7.3 Development of survivorship care: Social, economic, and political factors. The emergence of survivorship as a unique entity within cancer care has occurred against a backdrop of economic and sociopolitical forces, driven by metanarratives and ideologies embedded with biomedicine, that continue to shape how survivorship care evolves within our cancer care and primary care systems. Forces discussed here include a) corporatization of health care, espousing efficiency and scarcity ideologies, b) neoliberal ideology that supports individualism and self-care ideologies and c) specialization, which divides practices of practitioners and structures, further fragmenting the care environment. Critical examination of these forces and ideologies, within the context of how they shape survivorship care, is essential to understand how a continued singular focus on survivorship through a biomedical model lens may constrain the achievement of equitable high quality survivorship care.

³¹ Holism - A paradigm where the epistemology emphasizes the priority of a whole over its parts; the sum is greater than its parts. The ontology includes multiple subjective realities (Blackburn, 2008; Dossey & Keegan, 2013)

2.7.3.1 Corporatization of health care: Scarcity, efficiency and rationalization. The biomedical model's reductionist approach is enacted within cancer care systems to maximize efficiency and ration resources. Corporatization (commodification of health care), while attempting to improve efficiency, inadvertently also may objectify survivors and health care providers, reducing quality and access to care and health resources (Austin, 2011; Ritzer, 2011; Varcoe & Rodney, 2009). Corporatization can have negative impacts on people who experience marginalizing conditions within society (e.g. due to racialization, gender inequality, poverty, unemployment, disability), as the already complex system of care becomes more inaccessible to those who have low health literacy, inadequate social supports and other barriers (Freeman & Chu, 2004; Lynam et al., 2003). An example of corporatization's marginalizing effects includes care models based on definitions identifying survivorship beginning at the end of primary treatment. From an efficiency perspective, alignment of resources at the end of primary treatment prevents duplication of services; however, for marginalized individuals, this model misaligns resources beyond the time period that these resources can positively influence cancer survivorship outcomes. These individuals in particular require support early in the cancer trajectory, to improve early screening, detection and treatment so that survival and quality of life outcomes are optimized (Casillas & Ayanian, 2011; Maddison et al., 2011).

An ideology of scarcity further constrains decisions made at local (i.e. clinical) and system levels (Varcoe & Rodney, 2009), encouraging efficient movement of survivors through the cancer care system, possibly at the expense of other needs, such as addressing psychosocial issues or support for health promotion behaviors. Development of therapeutic relationships and relational practice is limited, while survivors with complex needs may be referred to multiple health professionals, further fragmenting care. The scarcity ideology supports prioritization of disease-focused survivorship care (e.g. disease surveillance) and coordination of survivorship

care across systems (i.e. specialized oncology and primary care) at the expense of more time and resource-intensive care (e.g. health promotion, psychosocial support).

This scarcity ideology is reflected in the development of survivorship care plans (SCPs) which have been held up as the key answer to improving efficient communication and care across health care settings (Howell et al., 2012; Rowland, 2011; Rowland & Ganz, 2011; Stricker & O'Brien, 2014). Initially, the tool was proposed as a strategy to help survivors move efficiently from an orderly system of care to a “non-system” after completion of primary cancer treatment, highlighting the role of the SCP as a band aid to improve communication efficiency across a fragmented “non-system” of survivorship care (Belansky & Mahon, 2012; Hewitt et al., 2006; Sofaer, 2009). Although a detailed template for the content of SCPs has been defined³², few care settings have implemented the SCPs due to resource implications (e.g. time to complete, lack of electronic patient record to retrieve required treatment and care information, lack of physician reimbursement for completion, lack of clear guidelines to make recommendations, concern that primary care providers do not have the knowledge to implement the care recommended in the SCP) (Fitch et al., 2014; Forsythe et al., 2013; Howell et al., 2011; Mayer, 2014; Salz et al., 2014). When the SCPs have been used, the content usually focuses on the disease surveillance aspects of survivorship care to communicate to the primary care provider, with little information about long term effects, health promotion recommendations, or psychosocial support. Rarely are

³² Survivorship care plans – A template outlining the key content to include was defined within the IOM report (Hewitt et al., 2006), including cancer treatment history; disease surveillance recommendations; anticipated late/long term effects including recommendations for screening, prevention and/or intervention; information on possible effects of cancer on partner/marital relationship, sexual functioning, work, parenting, and potential future need for psychosocial support; information on the possible insurance, employment, and financial consequences of cancer, including referral to insurance/legal/financial assistance; recommendations for health promotion (e.g. diet, exercise and weight maintenance); recommendations for genetic counseling, as appropriate; information on known chemoprevention strategies, as appropriate; information on survivorship-related resources; referral to specific follow-up care providers.

survivors involved in the development of their own care plans, to ensure their own beliefs, values and goals for care are included (Birken, Mayer, & Weiner, 2013; Forsythe et al., 2013; Stricker et al., 2011). SCPs, while intended to communicate the ongoing unique needs of survivors after primary treatment, have been shaped by structural factors and a scarcity ideology. SPC's largely have been reduced to a unidirectional documentation tool that excludes survivors' perspectives, is not contextualized to the individuals' needs, and is used as a quick fix for a broken cancer care system. Recent economic evaluations of SCPs have also revealed that they are neither cost effective, nor effective in improving outcomes compared to standard care (Coyle et al., 2014).

2.7.3.3 Neoliberal ideology, individualism & self-care. The backdrop against which the corporatization of health care is enacted includes a neoliberal ideology purporting individual free choice and equal opportunity for economic gain, and where individual benefit is valued over collective/societal benefit (Browne, 2001; Coburn, 2004). The biomedical model has perpetuated this focus on individualism within survivorship care in a variety of ways, including the manner in which evidence is generated and applied, how interventions are offered, and the emphasis on self-care strategies.

Biomedicine's reinforcement of individualized responsibility for health perpetuates efficiency discourses and deepens disparities in care (Sinding, Miller, Hudak, Keller-Olaman & Sussman, 2012). By placing responsibility for health in self-care strategies, the cancer care system is able to reduce health care expenditures (Baum, Begin, Houweling & Taylor, 2009). Many self-help and supportive care structures are located outside of the cancer care core budget, within research or "soft funding" income streams that absolves the biomedical system from placing value (and dollars) on health promotion strategies for survivors (see, for example, Wellspring, 2014). Many survivors must pay out of pocket for self-care practices, further highlighting the intersection of

structural factors such as socioeconomic status of individuals, and the effect on constraining agency and promoting health inequities.

2.7.3.3 *Specialization and dividing practices.* Although cancer survivorship is established as a separate phase within the cancer trajectory to improve access and quality survivorship care across a fragmented cancer care system in Canada, this separation may in fact contribute to the fragmentation problem. As Foucault (1982) argues, structures within health care systems objectify practitioners and separate them according role, location, and scope of daily activities. Specialization that compartmentalizes health professionals within specialties and health systems (e.g. specialized oncology; primary care systems) and roles (e.g. oncologists, primary care providers) exemplifies Foucault's notion of dividing practices. Identification of survivorship as a distinct entity within the cancer care system further divides practices, creating another layer of separation among and between disciplines, limiting opportunities for questioning and actively engaging in dialogue about ontological or epistemological assumptions undergirding health care (Dzurec, 2003). Without active questioning and critique among and between disciplines and health care systems, opportunities for addressing the structural constraints that perpetuate health inequities are missed, as are opportunities for considering ways to foster equity across and within groups. Instead, the focus of care remains at the individual level, without opportunities to see, critique and improve care for aggregates or groups. In Canada, although dialogue has begun between oncologists and primary care providers (CAPCA, 2010), these debates largely focus on systems of care and physician roles that promote biomedicine and its reductionist, disease-focused underpinnings.

The concept of navigation, embraced by many cancer care organizations as a solution to the disjointed cancer care system, also unwittingly may further fragment care (Pederson & Hack, 2010, 2012; Thorne & Truant, 2010). Following the introduction of patient navigator roles in

Harlem hospitals in the United States (US) to address unacceptable inequities in breast cancer outcomes between African-American and other vulnerable population groups and the wider population, a plethora of peer-led and professional patient navigator roles and strategies were implemented across the US, Canada, the United Kingdom (UK), and Australia (Fillion et al., 2012; Freeman & Chu, 2004; Pederson & Hack, 2010, 2012). Founded upon a distributive justice model to improve access to cancer care, navigation conceptualizes health as a commodity (i.e. something to be handed out by nurses and passively received by patients) (Jennings, 1996). When health is viewed as a commodity, important causes of inequities underpinning the health of individuals are missed. A lack of understanding of the determinants of health and other structural factors promoting inequities among individuals within groups creates a blind spot for all, including navigators, predisposing navigators to inadvertently perpetuate the marginalization of people and groups. The focus on healthcare access versus health outcomes within the navigation agenda therefore may undermine health professionals' ability to promote optimal, equitable health outcomes for people experiencing cancer (Reimer Kirkham & Browne, 2006). Strategies are required to integrate navigation within the health care system (or create a patient-centred system so that external navigation is not required), without the need for another layer of health professionals that further divides practices and system fragmentation.

2.8 Summary

In this review of the literature I explored the current Canadian cancer survivorship care context, including the political, social, economic, and personal factors that have shaped and continue to influence and shape the development of survivorship models of care and resources. Gaps and inconsistencies were identified that may inhibit rather than optimize equitable high quality cancer survivorship care. New knowledge and perspectives are needed to inform the future development of survivorship care models and resources that address survivors' needs at

both an individual and population level. Specifically, the perspectives of survivors regarding survivorship care are required. The social, economic, political and personal factors that influence survivors' access to and experiences of survivorship care must be understood if equitable, high quality care is to be provided.

CHAPTER THREE: Theoretical and Methodological Framework

3.1 Introduction

In the previous chapter, I identified numerous complexities inherent within the cancer survivorship experience, and the associated challenges in designing and achieving equitable high quality survivorship models of care and resources. There is general agreement that the care of cancer survivors in Canada is suboptimal. Continued reliance on the biomedical disease-focused model of care will not account for the complexities within individuals or the health care environment that shape and constrain survivors' abilities to have their supportive care needs met and to maximize their quality of life (Grinfeld & Earle, 2010; McCabe et al., 2013; McMurtry & Bultz, 2005; Sofaer, 2009). Contextual knowledge is required to inform the development of future survivorship models of care and resources, taking into consideration the complexities involved in the layering and intersection of factors that shape survivors' agency at individual and population levels, as well as offering direction for action in the development of survivorship care models and resources.

A variety of theoretical approaches offer direction to a study that describes the complexities involved in developing high quality equitable survivorship care models and resources. However, few theoretical approaches address the pragmatic action orientation required to move beyond simple description to making recommendations for action or change. Nursing's disciplinary framework, with its unique epistemology, is one such approach that allows for both description and action (Thorne, Reimer Kirkham & MacDonald Emes, 1997; Thorne, 2008b, 2011; Thorne & Sawatzky, 2014; Thorne, Stephens & Truant, 2016).

3.2 Theoretical Framework: Nursing's Disciplinary Logic

Nursing's disciplinary framework offers a theoretical scaffold within which to explore human

experience and diversity; social, political, historical and other contexts; social justice imperatives; ethical reasoning, intersectionality and complexity (Johnson & Ratner, 1997; Liaschenko & Fisher, 1999; Thorne, 1997; Thorne & Sawatzky, 2014). Further, as an applied discipline, nursing seeks to develop and contextualize knowledge for the purpose of action or change (Johnson & Ratner, 1997; Kagan, Smith, Cowling & Chinn, 2009; Reed, 2006; Rolfe, 2006; Thorne, 1997, 2011; Thorne & Sawatzky, 2007, 2014). To demonstrate the fit of nursing's disciplinary framework with the aims of this study, I describe nursing's mandate and key aspects of nursing's disciplinary epistemology and internal logic structure as it relates to the theoretical framework that has guided the methods for this study. Through the explication of the values, ideologies, and philosophies underpinning this nursing epistemology, I attempt to lay out a clear, logical and credible framework to defend and justify decisions made in the design, implementation and analysis of this study.

3.2.1 Nursing's mandate. Nursing enacts its mandate to contextualize and apply subjective and objective knowledge for the benefit of individuals, groups and aggregates (Johnson & Ratner, 1997; Purkis & Bjornsdottir, 2006; Thorne, 1997; Thorne et al., 1998). To purposefully create this context, nurses dialectically weave together empirically-based evidence with other sources of knowledge³³, such qualitative findings, shared clinical wisdom, pattern recognition, established practice, ethical knowledge and other “ways of knowing”, such as Carper's (1978) personal, aesthetic, intuitive and empirical knowledge; sociopolitical knowledge (White, 1995); and emancipatory knowledge (Chinn & Kramer, 2011; Kagan et al., 2009; Doane & Varcoe, 2013; Johnson & Ratner, 1997; Liaschenko, 1997; Pesut & Johnson, 2013; Purkis & Bjornsdottir, 2006;

³³ In using the term *knowledge* throughout this study, I am explicitly referencing subjective knowledge that is exclusively based on personal experience, intuition or revelation that does not constitute a shared form of knowledge. Evidence is a form of knowledge that is shareable and applicable beyond the immediate context of perceptions, experiences and beliefs (Johnson & Ratner, 1997).

Thorne, 2008b; Thorne & Sawatzky, 2007, 2014). Through this dialectical process of engaging with individuals within their context, and various sources of knowledge, nurses aim to “particularize the general”, finding meaningful ways to apply population-based evidence (i.e. from evidence-based medicine) to individuals’ unique situations. Further, as an applied health discipline with a mandate for action, nurses dialectically contextualize this knowledge to influence human experiences in ways that enact the moral agency and social justice imperative of professional practice (Pauly, 2013; Pesut & Johnson, 2013; Rodney et al., 2013).

3.2.2 Nursing’s disciplinary epistemology. Underpinning nursing’s mandate are a number of core values, theories and philosophic positions/approaches that help to shape and form nursing’s disciplinary epistemology. Foundational to nursing’s mandate is the core value of holism³⁴, viewing individuals, families, communities and societies as complex and dynamic entities striving toward health³⁵ within their own context. Underpinning this value is the philosophical position that people are complex contextual beings who exist in relation to others within social, cultural, political, and historical processes, and influenced and shaped by situations, context, environments and processes (Doane & Varcoe, 2013; Rodney, Burgess, Pauly & Phillips, 2013; Sewell, 1992). An imperative therefore exists for nurses to “know patients”, at the individual and aggregate levels, in such a way as to be able to contextualize knowledge to benefit those individuals and aggregates (Doane & Varcoe, 2013; Liaschenko & Fisher, 1999; Thorne & Sawatzky, 2014; Thorne, Stephens & Truant, 2016). In this study, the context within which survivors experience and access care and practice health behaviors was important to explore both

³⁴ Holism - A paradigm where the epistemology emphasizes the priority of a whole over its parts; the sum is greater than its parts. The ontology includes multiple subjective realities (Blackburn, 2008; Dossey & Keegan, 2013).

³⁵ Health is not merely the absence of disease, but rather a balance among basic human needs. Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity (WHO, 1946)

at the individual and aggregate level, allowing for the exploration of human commonalities as well as individual expression of variance. Perspectives of key stakeholders (e.g. survivorship program leaders, clinicians caring for survivors in the transition post primary cancer treatment, national leaders influencing survivorship care) who are perceived as part of the “context/influencing forces of survivorship care” were explored to better understand the context of care. Documents describing survivorship care policies, education and other resources were analyzed to identify contextual factors, including metanarratives and ideologies, shaping survivorship care experiences and opportunities.

Nursing’s philosophical underpinnings with regard to how knowledge is created (and what constitutes knowledge) offer some structure for this study. In addition, evidentiary sources of knowledge such as that gleaned through evidence-based medicine, as a discipline espousing relational practice (Doane & Varcoe, 2013), nursing values subjective and experiential knowledge as a source of clinical insight (Johnson & Ratner, 1997). This subjective and experiential knowledge informing nursing practice is co-constructed between the knower and the known (e.g. clinician/researcher/survivor) based on a constructivist philosophy of knowledge production/development. This knowledge is grounded in time and place, and as a result is temporal, changing with time and context. As with a social constructivist position on knowledge development, there may exist multiple, sometimes contradictory, realities (Tarlier, 2005). Rather than pursuing a singular truth (as per Popper, 1959), such as one “right way” to do something, nursing seeks to uncover truth-claims and draw upon multiple ways of knowing and evidence to determine the best way to do something within a particular context. Relevant theories, prior knowledge and experience brought to a clinical interaction are valuable and inform that interaction, and it is within the dialectic of the nurse-patient/nurse-community interaction that an iterative process of knowledge development occurs. Through the conscious use of reflection and

reciprocal interplay of theory and practice, knowledge is created *for and in* practice (Doane & Varcoe, 2009), highlighting nursing's praxis orientation (Chinn & Kramer, 2011; Kagan et al., 2009; Reed, 2006; Tarlier, 2005; Thorne, 1997). Through this praxis-oriented process, knowledge is developed to guide nursing's professional purpose, particularizing the general to inform the care of infinitely complex and unique human beings (Thorne, 1997; Thorne & Sawatzky, 2014). Within a research context, knowledge that is co-constructed through a praxis orientation involves a reflexive process between researchers and participants (Doane & Varcoe, 2009; Thorne, 2008b). This link between reflexivity and socially constructed knowledge then becomes a central epistemological assumption within this study.

Applied to the current study, this dialectical praxis orientation offered opportunities to explore how current standardized approaches to survivorship care (i.e. "the general") impact survivors' health experiences and health management strategies. Opportunities to contextualize these standardized approaches for individuals ("the particular") are offered through a praxis orientation.

3.2.3 Pragmatism. Pragmatism³⁶ is a philosophic perspective underpinning nursing's disciplinary epistemology with considerable relevance for this study. Returning to nursing's mandate for *action*, pragmatism focuses on the practical implications of taking up a particular theory or perspective. According to James (1907/1997), rather than focusing on whether or not something is true, pragmatism asks, "what *difference* would this mean if it were true"? (p. 112). Through being open minded and exploring as many ideas or versions of the truth as possible, the

³⁶ I include a very broad view of pragmatism that spans the works of many important pragmatists. Pragmatism was first named by William James in 1898, as a way of *doing* philosophy that respected all viewpoints and used theories as instruments to settle disputes. Dewey later added the perspective of "learning as doing", applying previous experience to new experiences to seek new ways of understanding. Rorty (1987) and others, as neopragmatists, added in a moral/ethical base for judgment about truth-claims. Rorty also promoted the rejection of binary thinking, redefined inquiry as a process of trying out new beliefs to determine the utility and fit with the problem at hand, and redefining progress as less about achieving forward direction and more about richer human activity (Warms & Schroeder, 2009).

pragmatist draws upon an ethical base to create opportunities to improve situations and solve problems (James, 1997; Rorty, 1987). A variety of sources of knowledge are considered (e.g. human logic, experience, empirical evidence) and none are preferenced *a priori*. Binary thinking is rejected because pragmatic thinkers blur the distinctions between traditionally held opposing concepts (e.g. subjective/objective, fact/value, agency/structure, true/false) (Rorty, 1987). By blurring these concepts and being open to a wide variety of sources of knowledge, possibilities for new ways of finding the best solution or answer for that time, place and situation are maximized (Rorty, 1987). It is important to note that solutions to problems are not judged by moving forward in the traditional sense; rather, progress is defined as fostering richer human activity. “We should think of human progress as making it possible for human beings to do more interesting things and being more interesting people, not as heading toward a place which has somehow been prepared for us in the past” (Rorty, 1987, p. 45). Opportunities to explore solutions to complex issues are maximized through the use of a pragmatic approach.

Theories hold a unique place within pragmatism and are used as a means to an end. Using a pragmatic approach, “Theories thus become instruments, not answers to enigmas, in which we can rest. Pragmatism unstiffens all our theories, limbers them up and sets each one at work” (James, 1997, p. 27).

Applied to the current study, pragmatism aligns with a number of issues highlighted in the literature review and offered some direction for study design and analysis. As per pragmatism’s focus on achieving some pragmatic end or action, it is essential to have at least a general sense of what that end looks like. Within this study, the general end in view included insights and recommendations regarding the design of an equitable high quality system of care for cancer survivors, which addresses survivor’s needs both at an individual and population level. Because the end must be meaningful to the survivors themselves to ensure a patient-centered system of

care, a dialectic process of refining and shaping this end in view with survivors was necessary. Many relevant and useful forms of knowledge were important to consider in achieving this end in view, including, for example, theories, philosophic perspectives, logic, and experiences. Relevant sources of knowledge were identified as helpful to frame the study from the beginning; others became apparent as the study unfolded, in relation what was most useful to at that time and place to achieve the desired end³⁷.

The literature review for this study highlighted gaps in how current survivorship care is not designed or enacted to address the full range and complexity of survivors' needs. Rather than considering the complexities inherent in the survivors themselves, or the various forces influencing survivor's unmet needs, the current care system groups individuals with commonalities according to the social determinants of health (e.g. ethnicity, gender, location), point in the cancer trajectory (e.g. end of primary treatment, cancer recurrence), type of cancer (e.g. breast, prostate), symptoms (e.g. infertility, peripheral neuropathy), practical concerns such as return to work, and health promotion activities such as screening or lifestyle change. These essentialized groups then form the foundation for developing survivorship care models and resources that may not acknowledge or address the complexities within individuals and may create inequities in access to quality care for many. A new way of viewing cancer survivorship care is required to disrupt these old patterns of essentializing individuals according to one or more deficits/needs, toward a system of care that considers the intersectional nature of social disadvantage, agency and structure for individuals as well as aggregates. To orient this study to explore these complexities within survivorship care and disrupt old patterns, I loosely drew upon

³⁷ This is not to suggest that knowledge sources will be applied randomly, without critical thought or reflection, or outside of a framework; Rather, nursing's disciplinary epistemology forms the framework for this study, which encourages the thoughtful, reflexive use of theories and knowledge sources as practical instruments to achieve pragmatic ends (Doane & Varcoe, 2005; Rorty, 1987).

intersectional (see for example, Hankivsky, 2011) and critical (see for example, Battersby & Bailin, 2011) perspectives.

3.2.4 Intersectionality as a heuristic. Intersectionality³⁸ has been used as a concept to describe the multiple constraints and layers of contexts that organize peoples' experiences (Anderson, 2006; Anthias, 2013; Dhamoon, 2011; Hankivsky, 2011). As a heuristic to explore and understand differences across and within groups, and the processes by which these groups are formed and maintained, intersectionality can aid in exploring the complexities imbedded within cancer survivorship models of care. Intersectionality shifts the focus from essentializing identities and categories of difference (e.g. gender, type of cancer, immigrant status) to “an analysis of the interactive processes of differentiation that produce and govern subjects, and how these processes work in relation to the system of domination” (Dhamoon & Hankivsky, 2011, p. 31).

Recognizing that individuals within groups are diverse, and that dynamic interactions exist between individual and institutional factors, intersectional approaches include an analysis of the individual or group to be integrated with an institutional analysis to understand how they mutually influence and shape each other (Dhamoon, 2011). In this way, multiple, complex, and varied axes of differentiation come together (e.g. subjective, experiential, economic, political) to produce something unique and distinct from any one form of difference standing alone (Dhamoon, 2011; Dhamoon & Hankivsky, 2011; Hankivsky, de Leeuw, Lee, Vissandjee & Khanlou, 2011).

The epistemology underpinning of intersectionality generally aligns with nursing's disciplinary epistemology and pragmatism and is therefore was seen as a good fit for this study.

³⁸ Intersectionality – While the language of intersectionality has been popularized over the past two decades, disagreement exists regarding whether intersectionality is a theory, framework, concept, paradigm, lens, heuristic, or other organizing structure (see for example, Anthias, 2013 for an overview of these debates). For the purpose of this study, I draw upon intersectionality as a heuristic to explore complexities within survivorship care.

Within intersectionality, truth-claims and knowledge are socially constructed, complex, and influenced by time and place. Subjective and experiential knowledge are an important source of insight, and the self cannot be separated from the social (Dhamoon, 2011; Hankivsky et al., 2011). Rather than a singular focus on binaries (e.g. man/woman), the focus of an intersectional approach is on the variations within, between and among binaries. Similarly, social aggregates are examined within and in relation to each other, highlighting socially produced differences.

Applied to this study, intersectionality offered a way of examining multiple angles of vision on how factors interact and layer to advantage and disadvantage individuals and groups within survivorship models of care. While most proponents of intersectional approaches would agree that it is impossible to explicate all of the possible intersections and complexities within a phenomenon, it does present a way of viewing that phenomenon that strategically depicts its complexities (Hankivsky, 2011). Some intersectional researchers and social scientists have suggested practical approaches to exploring the intersections among and between social groups and individuals therein. For example, Anthias (2013) suggests four general foci to explore social arenas, including organizational (structural position), representational (discourses), intersubjective (practices), and experiential (narratives). Applied to this study, these foci³⁹ were applied to explore and explain aspects of how survivorship care is shaped and enacted. For example, an intersectional lens was used to consider how the biomedical model has shaped the development of tumor-group based survivorship clinics (structural), how individuals within particular support groups reinforce the existence of that support group through relating to “people like us” (practices), and how various narratives embedded within survivorship influence how individuals engage in the existing care structures (narratives). While this exploration is helpful to

³⁹ I did not intend to use these foci as categories to be filled, but rather as a general guideline to begin to explore the complexities within survivorship care.

explicate the complexity involved in survivorship care, intersectionality as a heuristic does not offer directionality in terms of moving this understanding/new knowledge into action. Nursing's disciplinary epistemology and pragmatism offered a structure within which to move this new knowledge into action for the benefit of survivors.

While intersectionality has grown out of critical feminist theory (Collins, 1990; Crenshaw, 1991), which highlights intersecting systems of oppression and domination shaped by power, my intent was not to operate *primarily* from a conceptual lens of power within the study. Instead, I wanted to locate and explore power within and among a broader context of factors that shape survivorship care. Drawing upon Foucault's (1980) notion of power, I took the position that “power is not a commodity, something to be owned or centralized...instead [power] operates in micro practices of all social relations” (p.89).

3.2.5 Critical perspectives. To aid with the explication of the complexities embedded within cancer survivorship care (and with a theoretical commitment to praxis as a process and outcome of this study), I drew upon critical perspectives⁴⁰ and strategies such as post structural deconstruction. Researchers taking a critical perspective in their research generally share value-orientations of social justice and action toward positive social change or emancipation (Battersby & Bailin, 2011; Carspecken, 1996; Crotty, 1998; Morrow & Brown, 1994). Using a critical inquiry approach, questioning and reflection on the values, assumptions, patterns and processes

⁴⁰ I use the term “critical perspectives” in its broadest sense, rather than focusing on a particular critical theory, such as Critical Social Theory. Broadly speaking, a *critical perspective* is an approach to inquiry that includes questioning, reflexivity and analysis of the patterns and processes that shape human experiences (Battersby & Bailin, 2011). Through this critical inquiry approach, new knowledge is developed to challenge the status quo and the power relations that produce inequalities, in ways that can lead to advocacy, community action and social change (Crotty, 1998). *Critical Social Theory* (for example, Habermas 1968/1971), is a specific critical theory which focuses on reason, language and rational argument and a normative foundation for social critique. Assumptions include unequal power relations and oppressive structures within society. Emancipation is the goal, seeking liberation from power and domination arising from social, political, economic and ideologic conditions (Boutain, 1999; Hbermas, 1968/1971).

that shape human existence become mechanisms to expose inconsistencies and disjunctures. In the broadest sense, "...critical inquiry remains a form of praxis – a search for knowledge, to be sure, but always emancipatory knowledge, knowledge in the context of action and search for freedom" (Crotty, 1998, p. 159).

Post-structural deconstruction is one critical strategy that aims to expose the structures underpinning a phenomenon such as cancer survivorship care, exposing and disarming power relations and fragmenting metanarratives through making inconsistencies apparent (Derrida, 1974; Reed, 2009; Rolfe, 2005). Deconstruction untangles and uncovers complexities, finding meaning beyond the apparent and offering insight for action toward a socially just world (Lather, 1986, 1991). According to Foucault (1976/1990), the influence of power is everywhere and plays a central role in the social construction of a range of structures from political and organizational structures to the activities of everyday life. Foucault (1990) also positions discourse as the medium through which power relations are maintained and reproduced. Using a deconstructionist lens, discourses (e.g. dialogue, text) can be examined to explicate structural manifestations of power (Dzurec, 1989). In this way, deconstruction aids in understanding the implications of particular ways of considering phenomena (Kagan et al., 2009).

In this study, by taking a critical perspective and using deconstruction as a strategy, I hoped to expose the metanarratives underpinning cancer survivorship care. I hoped to uncover blind spots, unperceived problems and contraindications so as to offer new perspectives from which to re-examine the social justice and moral ends enacted within survivorship care. I assumed that discourses, such as those located in written text (e.g. policy documents, survivor education programs, survivorship clinical guidelines), and those enacted through dialogue with survivors

and key stakeholders might hold opportunities for deconstruction and the reconceptualization⁴¹ of survivorship care that equitably addresses the needs of individuals and aggregates.

Before fully taking up deconstruction as a strategy for explicating complexities in this study I considered two important critiques of post-structuralism. The first critique relates to the attention paid to human agency. Power is positioned within society as a structural force capable of suppressing/inhibiting the enactment of human agency. Deconstruction, without attention to human agency, could unwittingly position individuals and groups as oppressed or marginalized (Layder, 1997). The second challenge, as it related to this study, was the lack of contribution of post-structuralism to the practical strategies to overcome oppression and inequality (Misgeld, 1992). For the purposes of a study on cancer survivorship care that is informed by nursing's disciplinary epistemology, I understood that deconstruction must be used judiciously, within a theoretical scaffolding that allows for human agency to be expressed and a pragmatic action be taken.

In summary, the theoretical framework for this study that aimed to generate insights and recommendations regarding the design of an equitable high quality system of care for cancer survivors, one which address survivors' needs both at an individual and population level, required opportunities for examining the phenomenon from multiple angles of vision. Using nursing's disciplinary epistemology underpinned by pragmatism to support an action orientation, I created a theoretical scaffold that brings in an intersectional lens, critical perspectives and deconstruction to explicate the complexity embedded within survivorship care. This theoretical scaffold and logic structure, embedded within nursing's disciplinary epistemology, gives direction to the development of the study methodology, described in the next section.

⁴¹ I acknowledge the apparent epistemological incommensurability of applying both a constructivist and deconstructionist approach to the same data. However, when applied within a pragmatic framework, both approaches may be thoughtfully used as strategies toward a pragmatic end

3.3 Methodological Framework

3.3.1 Introduction. In the previous section I outlined an intellectual structure that serves as the foundation upon which design decisions were made about the strategy of inquiry. Nursing's disciplinary epistemology and internal logic structure formed the scaffolding within which an intersectional lens and critical perspectives offered direction to achieve the study end in view. That end in view was to develop insights and recommendations regarding the design of an equitable high quality system of care for cancer survivors – one that will address survivors' needs both at an individual and population level.

Using nursing's disciplinary epistemology as the theoretical scaffolding within which to frame this study required a methodology that provided opportunities for description, interpretation, and pragmatic action (Thorne, 2008b, 2013a; 2016; Thorne et al., 1997; Thorne et al., 2004). Moving beyond the conventional social science methodological traditions⁴² that seek only to describe and theorize rather than to act, in this study I employed interpretive description (Thorne, 2008b, 2013a; Thorne et al., 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004) as the approach to inquiry, explicitly drawing upon a nursing epistemological lens (Thorne, Stephens, & Truant, 2016).

3.3.2 Interpretive description. As an applied qualitative methodology, interpretive description uses nursing's disciplinary epistemology to generate new insights about clinically relevant phenomena for the purpose of generating change (Thorne, 2008b, 2013a; 2016).

Interpretive description draws upon pragmatism and analytic maneuvers drawn from

⁴² Social science methodological traditions examples include phenomenology, grounded theory and ethnography. These methodologies, while useful for generating theory about a clinical phenomenon, do not offer strategies to explore how that theory, essentially useful at the general level, can be applied to infinitely unique individuals. Interpretive description offers this opportunity to orient the research logic around the clinical problem, testing out various theories to pragmatically address the clinical situation (Thorne, 2011)

phenomenology, ethnography, grounded theory, naturalistic inquiry and other classic qualitative approaches while using logic, reason, and critical self-reflection as important processes within this strategy of inquiry (Thorne, 2008b). The product of interpretive description is “a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied, and also accounts for the inevitable variations within them” (Thorne et al., 2004, p. 4).

Thorne (2008b) identifies a set of assumptions to underpin this strategy of inquiry, which, when carefully adhered to, supports the use of varied research methods within interpretive description studies, ensuring “a coherence that distinguishes the products of interpretive description from those derived from blended approaches or from generic qualitative description” (Thorne, 2008b, p. 75). The assumptions and philosophical positions underpinning interpretive description align well with those within this study’s theoretical framework (i.e. nursing’s disciplinary epistemology and pragmatism, sensitized by an intersectional lens and critical perspectives). These points of alignment include:

- a) Constructing knowledge (i.e. meaning and knowledge are socially constructed; the inseparable relationship of the knower and the known; the importance of noting the context when creating knowledge),
- b) Attending to the commonalities among groups as well as the individual variations within,
- c) Acknowledging the researcher as an instrument bringing subjective and objective knowledge as a source of clinical insight, and
- d) Acknowledging existence of multiple realities that may be contradictory (Thorne, 2008b; Thorne et al., 1997; Thorne et al., 2004).

It is important to highlight that the theoretical framework within this study offered an interpretive lens/heuristic through which to approach design and conduct of the study, rather than “a container into which the data must be poured” (Lather, 1991, p. 62). Taking up critical perspectives and ongoing reflexivity throughout the design and conduct of the study ensured that these theories did not unnecessarily obscure important and relevant aspects of cancer survivorship care, nor provide a rigid *a priori* structure that inhibited the appropriate unfolding of the phenomenon under study (Sandelowski, 1993).

3.3.3 Scaffolding the study⁴³. The initial position from which I designed this study was informed by the literature review, theoretical alliances, nursing’s disciplinary epistemology, and my own positioning of ideas and experiences in relation to cancer survivorship care (Thorne, 2008b, 2013a). This study scaffold created a coherent logic model within which to use interpretive description to “serve as a referee, running interference against the challenges of methodological pursuits” (Thorne, 2013a, p. 279). Within this study, the study scaffold gave direction to a number of design decisions, which are described throughout the remainder of this chapter.

As an interpretive description approach to inquiry positions the researcher as an instrument of the study, it is important to make explicit the researcher’s ideas, motivations, biases, and consequent angle of interpretive inquiry, as this may shape how the study is framed and conducted (Thorne, 2008b). This explicit positioning of the researcher enhances credibility and defensibility of the interpretive description study, maintains alignment with an inductive

⁴³ Earlier versions of interpretive description (Thorne et al., 1997; Thorne et al., 2004) used the term “analytic framework” to refer to the background knowledge and disciplinary orientation that a researcher brought to a study. The authors recognize that this term was somewhat misleading, suggesting that data analysis was explicitly guided by a predetermined conceptual structure. *Theoretical scaffolding* is the newer term employed to indicate the foregrounding and scholarly positioning within the study (Thorne, 2008b).

approach to knowledge generation, and offers insight into any potential power imbalances between the researcher and subject.

Specific to this study, I bring beliefs, values and experiences about the complexities associated with enacting whole person patient centred care that is equitable and high quality. As a nurse, I bring to this study more than 25 years of experience in clinical, education, leadership and research roles which allowed me to participate in a number of initiatives, shaping my perspectives on equitable high quality cancer survivorship care. Three experiences stand out as particularly relevant and influential, including a) taking a leadership role in improving models of care within a provincial cancer treatment agency, b) exploring patients' and family's needs for survivorship care through the lens of complementary and integrative medicine decision support and research, and c) involvement in national survivorship working groups to set a national cancer survivorship agenda in Canada.

3.3.4 Sources of data. The theoretical scaffold framing this interpretive description approach to inquiry gives direction to the social construction of knowledge for this study. Methodological commitments inherent in this scaffolding include:

1. Include multiple angles of vision/sources of data to include individual and aggregate perspectives and to enhance study credibility.
2. Survivors' and key stakeholder perspectives, including those who might be considered "outliers" or on the margins ought to be included in the evolving selection criteria.
3. Interview guides ought to be initially based on existing knowledge (and gaps in knowledge) about cancer survivorship care, with opportunities for evolution of the interview (and subsequent interviews) as themes and perspectives emerge.

4. View participant perspectives as being influenced by ideological, social, political, economic, personal and other factors; design the initial interview guide with these factors in view.
5. Build in opportunities to explore individual and aggregate perspectives.
6. Include concurrent data collection and analysis, sharing patterns and themes in the data with participants to co-construct knowledge with participants.
7. Explore opportunities to pragmatically apply new knowledge from this study to improve cancer survivorship care

With these methodological commitments in view, a variety of sources of data were used to identify and explore insights and recommendations regarding design of an equitable high quality system of care for cancer survivors that address survivors' needs at both the individual and population level. Within this interpretive description study framed by nursing's disciplinary epistemology, critical textual analysis of key survivorship documents (e.g. policies, guidelines), a secondary analysis of a sample from the Communication in Cancer Care (CCC) database (Thorne et al., 2014), and interviews with both survivors and stakeholders were utilized as data collection methods to allow for inductively create new knowledge via social processes using, logic, reason and critical appraisal. Each of these four sources of data is described separately, followed by an explanation of the strategy that was used to integrate findings from each of these data sources.

3.3.4.1 Survivorship documents: Critical textual analysis. Documentary sources of data can play a role in adding an alternative angle of vision on a phenomenon within an interpretive description study (Thorne, 2008, 2013a). In this study, documents such as survivorship reports, policies, practice guidelines, programs, toolkits, resources and educational materials were explored and analyzed to uncover important beliefs, opinions, and attitudes about cancer

survivorship care in Canada. These documentary sources were selected based on the literature review presented in Chapter Two and a scanning of websites, programs and organizations that might house documents which could provide insights into the degree to which high quality (equitable) survivorship care is/has the potential to be available in Canada. My professional experience related to cancer survivorship at the local, provincial and national level, and my clinical expertise informed the possibilities and selection of documentary sources. The focus or “sampling frame” for these documents included concepts of cancer survivorship, equity, navigation, person centered care, and high quality care. Data collection and analysis of these documentary sources occurred concurrently, and themes and patterns discovered within and across documents informed the development of survivors and stakeholder interview guides.

3.3.4.2 Communication in Cancer Care database: Secondary analysis. This qualitative database houses interview transcripts of 125 adult cancer patients offering over 500+ interviews over a 7-year period (2005-2012) focused on understanding cancer patients’ changing communication needs and preferences across the cancer trajectory (Thorne et al., 2014). A subset of these interview transcripts (N= 14),⁴⁴ that “explicitly addressed exemplars and/or recommendations pertaining to communication in the end of primary treatment phase” (Thorne & Stajduhar, 2012, p. 231) had been extracted and analyzed by Thorne and Stajduhar (2012) to explore cancer patient perspectives and needs regarding communication in the transition to survivorship care, with the aim to better inform survivorship supportive care services and

⁴⁴ This subset of the larger database includes an average of 5.3 interviews for each of the 14 individual patients, which consists of 12 women and two men ranging in age from 34 to 73 (mean=53.42). Primary cancer sites include seven breast, two hematological, two gynecological, one prostate, one gastrointestinal, and one lung. The study was conducted in British Columbia, Canada (Thorne & Stajduhar, 2012). However, since the publication of this study, additional participants were identified who are eligible to be included for analysis within the secondary analysis for the current purpose. As such, the number of participants for inclusion within the current study was ultimately 19.

systems. As it was anticipated that these transcripts would provide useful insights and recommendations about improving cancer survivorship care in the context of the three other data sources for the current study (i.e. survivor and stakeholder interviews and survivorship document analysis), this subset of the larger cohort was the focus of the analysis for this study, and transcripts from an additional 5 patients within the data set were later added bringing the total to 19.

Secondary analysis of qualitative data has recently gained attention as a valuable source of data when specific issues are considered regarding the nature of the existing data, ethical and legal considerations, and matters of voice and representation (Heaton, 2004, 2008; Thorne, 2013b). These issues are relevant to this study of cancer survivorship care. The first issue addresses concerns about the nature of the existing data and the epistemological and methodological fit with the secondary study. The original study using this subset of survivors (Thorne & Stajduhar, 2012) used interpretive description and nursing's disciplinary epistemology to frame the study and conduct the analysis, which is similar to the current study on cancer survivorship care and lays the foundation for a good fit between the data and the current study. Semi structured/open ended face-to-face interviews were conducted in the original study in a naturalistic setting to explore communication pertaining to communication in the end of primary treatment phase. It is important to consider that the framing of the questions in the original study, and the interaction between the participant and researcher during the interview will have shaped the content and structure of the transcripts, which was taken into consideration for this study.

Participants in the original study were volunteers, purposefully sampled through multiple approaches, and live in the same province within which the secondary study was conducted. Further, the Principal Investigator in the original large database studies (Thorne et al., 2014) and the subsequent communication at the end of primary treatment subset study (Thorne & Stajduhar,

2012) was also the supervisor for this current doctoral study. This continuity ensured that the secondary study fits well within the original epistemological and methodological commitments of the database, and that the new layer of study analysis proceeded appropriately within these boundaries.

Ethical and legal concerns regarding using the CCC database for secondary analysis were also considered. Initial ethical approval for the CCC database (UBC BREB # H09-01711) included informed consent to use de-identified transcripts for other research purposes in the future, beyond the original study. Also considered were the degree to which the secondary study questions differed significantly from the original questions (to which the participant consented to participate). This ensured that participants' consent was not unduly taken advantage of for a subsequent study that went in a significantly different direction to that which was agreed upon (Thorne, 2013b). Although the original study purpose and questions focused mainly on aspects of communication over the cancer trajectory, the goal of the original study was to inform the development of a cancer care system that optimally addresses cancer patients' needs and perspectives (Thorne et al., 2014). This secondary study shared a similar end in view, albeit focusing specifically on the survivorship phase of the cancer trajectory, and as such, aligned well with the intent of the original informed consent.

The third issue to address when undertaking a secondary analysis of a qualitative database pertains to matters of voice and representation (Thorne, 2013b). Concerns about wandering away from the initial intent and "voice" of the participants within a secondary analysis were addressed by continuous critical reflection on the transcripts in their natural state in terms of time and context. Although a secondary analysis applies a new set of questions, as was done in this case, it is essential to consider the influence of the original time and context in interpreting the data within the new lens. Without a detailed understanding of the context within which the data were

collected (a key philosophical underpinning of interpretive description and naturalistic inquiry), it would be difficult to go beyond the words within the transcripts to consider the influence of the context in shaping of the data. As such, in the current study, a secondary analysis of a subset of the CCC database acted as an alternative angle of vision. When combined with survivor and stakeholder interviews and critical documentary analysis, the secondary analysis of the subset of the CCC database assisted in adding depth and richness to exploring and explaining the interplay of factors which shaped access to and experience of survivorship care. Themes and patterns identified as a result of the secondary analysis also informed the development of survivor and stakeholder interview guides.

3.3.4.3 Participant interviews: Survivors and key stakeholders. As a prime source of subjectively derived knowledge, survivor and key stakeholder interviews were conducted. These interviews focused on understanding how structural and contextual factors (e.g. social, political, economic, personal) layer and intersect to influence survivors' access to and experience of equitable high quality cancer survivorship care.

The experience of survivorship care, from the perspectives of survivors, contains a multiplicity of individual and shared elements that I hoped to capture via participant interviews. Similarly, key stakeholders offered important insights into the factors that layer and intersect to influence survivors' experiences of and access to survivorship care. Using one-on-one interviews engages the researcher in the interview situation to better understand individual stories and experiences within identified patterns across aggregates. This knowledge can provide important insights into how to apply knowledge about aggregates to individual cases (Thorne, 2008b; Thorne & Sawatzky, 2014; Thorne et al., 2004; Thorne et al., 1997).

3.3.4.3.1 Cancer survivor interviews. Purposeful sampling was utilized to maximize variation among survivor participants across a range of demographic, personal and contextual factors (e.g.

age, type of cancer, time since completion of primary treatment, cure/palliative/long term metastatic, rural/urban, immigration status, SES, use of complementary and integrative therapies, experiencing a range of late symptom/side effect trajectories). As data collection and analysis occurred concurrently, sampling evolved over the study in response to themes and patterns and relationships identified in the data. It is often not until the researcher has begun to formulate relationships in the data that one can begin to understand the more relevant variables that may add relevant depth and richness to the sample (Glaser, 2002). To maximize the variation among survivor participants, strategies were employed such as selecting “outliers”, or those who are significantly different from those participants sampled so far, and/or did not fit the pattern emerging in the data. Further, participants were explicitly sought to explore variables that are known to promote disparities among cancer survivors, such as the intersection of poverty, poverty and advanced age in head and neck cancer (So et al., 2013). A contrasting case could be examined that considers intersection of high SES and an urban setting in breast cancer. Rather than examining these specific cases per se⁴⁵, these interviews were an opportunity to explore and contrast these cases as exemplars of how factors might influence one other to promote or hinder access to equitable high quality cancer survivorship care.

Inclusion criteria for survivor participants included: 18 years of age or older, diagnosed with cancer as an adult (when at least 18 years of age) and having completed primary cancer treatment. They had to be able to speak and read English, and willing to participate in one or more interviews. Survivors with non-melanoma skin cancer were excluded from the study.⁴⁶

⁴⁵ It was not my intent to set up binaries or essentialize individuals/groups through this comparison of cases.

⁴⁶ Non-melanoma skin cancer patients generally have minimal engagement with the cancer treatment system (if at all), minimal side effects, and a significantly different survivor trajectory from other cancers

A total of 34 survivor participants were ultimately recruited via hard copy and electronic posters/flyers (see Appendices A and B) in public and private spaces in the Lower Mainland (and around the province to obtain perspectives from those living in rural/remote areas) and letters of invitation. Locations such as health food stores, churches, community centers, primary care physician offices, BC Cancer Agency (and specifically the survivorship program), the British Columbia Family Practice Oncology Network (FPON) newsletter, the Complementary Medicine Education and Outcomes (CAMEO) research program webpage, community based integrative medicine programs (e.g. Connect Health)⁴⁷, community cancer support groups, and regional community cancer advocacy groups (e.g. Ovarian Cancer Canada; Prostate Cancer Canada, Brain Tumor Foundation, Leukemia/lymphoma Foundation).

A semi-structured open-ended interview guide (see Appendix B) was used to explore survivors' perspectives and insights regarding their experiences of engaging with/using the survivorship care system, including how/to what degree their health needs were met, and any support for the practice of health management strategies. Also, survivors' insights into how to design equitable high quality survivorship care models and resources to best meet survivors' needs were included as a topic for discussion in the interview. Drawing upon an intersectional lens to explore the layering and intersection of factors influencing survivors' engagement with the survivorship care system, the interview also included trigger questions such as any perceived barriers or facilitators to accessing high quality survivorship care. This interview guide served as

that does not carry the same impact on physical, financial, practical, informational and other needs (Kasparian, 2013).

⁴⁷ Connect Health, an integrative medicine program is run by 2 medical doctors with additional training in integrative medicine, working within an interprofessional team of naturopaths, massage therapists, dieticians, etc. This clinic is not cancer specific, but they do have a fair number of cancer survivors. They also do group medical visits so that people can participate in health promotion for free, covered by MSP

a starting point with initial survivor interviews and evolved throughout individual and subsequent interviews with other survivors, in relation to the themes and patterns identified in the individual interviews and across aggregates.

Ethical consent was obtained for the study from the University of British Columbia Behavioral Research Ethics Board (UBC BREB # H14-0382) and maintained throughout the study. Informed consent was obtained from individual survivors (see Appendix D), each of whom also completed a demographic survey (see Appendix E) and face-to-face (preferred) or telephone interviews lasting 30-90 minutes, in a place of their choosing.

All interviews were digitally recorded and transcribed verbatim, with only a non-identifying signifier attached with each interview. A master list matching non-identifying signifiers and participant names was kept in a locked drawer, separate from the transcripts. This drawer could be accessed only by the doctoral student researcher and supervisor. Participants were told that they could withdraw from the study at any time, and that any part of the digital recording/transcript could be erased upon request without compromising their care.

Although the study as designed aimed for maximal variation and diversity among the sample to foster credibility of the study, it was recognized that it would be impossible to include every possible variation and complexity within and among individuals. Rather than relying on notions of “saturation”⁴⁸ to determine when sampling is complete and no new information will arise from further sampling, interpretive description methods relies on other strategies to enhance study credibility with regard to sampling completeness. These strategies to determine sample size

⁴⁸ Generally, in other “pure” qualitative methodologies such as phenomenology and grounded theory, the notion of “saturation” has been used to determine when sampling is complete and a credible truth claim about a phenomenon can be made. Critics have suggested that data saturation can never be achieved, as it is impossible to sample for all the infinite complexities that exist in individuals and aggregates (Thorne & Darbyshire, 2005).

targets within an interpretive description study include an assessment of the degree to which the phenomenon of study is developed within the literature, the level of interpretive description desired as a result of the study (i.e. documentation of superficial similarities and differences across cases versus a more nuanced comprehensive portrayal of multiple facets of a clinical phenomenon), and pragmatic circumstances associated with conducting the study itself, such as the ability to access cases/individuals who can provide insight into the phenomenon under study (Thorne, 2008b, 2013a; 2016).

In the current study, sample size was determined based on the assessment that every cancer survivor has a story to tell regarding their experience of using the health care system post completion of primary treatment (i.e. the phenomenon under study is common versus rare). Further, as the existing literature had documented only superficially the experience of survivors using the cancer survivorship care system, and largely had not included survivors' perspectives regarding recommendations to develop an equitable high quality survivorship model of care, a more nuanced comprehensive depiction of this phenomenon was the aim of this study. Although I had initially proposed to interview 15-20 survivors, the diversity of perspectives and my increasing appreciation for context led me to continue the data collection to the final number of 34.

In addition to the interview transcripts, I took field notes of observations throughout the survivor interview. The field notes included, for example, non-verbal communication expressed by the survivor, physical appearance, or contextual factors such as time of day, presence of others, or other relevant contextual events immediately prior to the interview. Researcher reflections on the interview process, content, or other insights generated as a result of the interview were also be recorded in the field notes. These field notes were considered data within the study and used as an additional angle of vision to add to add context and aid in interpreting

transcript data. Also, these field notes (specifically the researcher insights and reflections) assisted in making explicit the logic/audit trail as decisions were made about data analysis.

3.3.4.3.2 Key stakeholder interviews. Purposeful sampling was also used to recruit 12 key stakeholders across a range of survivorship and cancer care programs, services and resources. Key stakeholders provided insight into the current and desired state of cancer survivorship care in Canada, as well as suggestions to minimize disparities and improve equitable access to high quality cancer survivorship care for all. In addition to survivors' perspectives and documentary sources of knowledge, key stakeholders' perspectives added an angle of vision that had not yet been shared collectively or documented in the literature. These stakeholders were expected to have expertise and insights about the development and implementation of survivorship care in Canada, adding to the depth and breadth of the data for answering the current research questions. In particular, stakeholders brought a perspective on possibilities for evolving an equitable high quality cancer survivorship care system despite economic constraints within the health care environment.

Stakeholders were purposively sampled to represent a range of perspectives within and outside of the cancer and survivorship care system. As discussed within the literature review in Chapter Two, the biomedical cancer care system may not be well positioned to continue to meet the holistic needs of the increasing numbers of cancer survivors. There may be health professionals and care approaches or models other than the current primary care physician and/or oncologist follow up that better meets survivors' long-term needs, such as, for example, a palliative approach to chronic illness or nurse-led survivorship care. Key stakeholders were therefore sampled to reflect a multiplicity of models, practitioners, and systems of care. Further, sensitized by an intersectional lens, stakeholders were purposively sampled to include political, economic, historical, social and other structural factors/perspectives that might shape the development of

survivorship models and types of practitioners involved. As the end in view for the current study was to make recommendations regarding the design of a high quality equitable survivorship system of care for survivors that is reflective of features that may have more broad (national/international) applicability, stakeholders were sampled from across the country, representing national, provincial, and/or local perspectives.

Similar to the survivor interviews, key stakeholder data collection and analysis occurred concurrently, so that sampling evolved over the study in response to themes and patterns and relationships identified in the data, within the parameters of the overall study aims. The initial sample size estimate of 10 to 12 had been based on the following considerations: all stakeholders having a perspective on current and envisioned survivorship models of care; the current literature documenting only a limited view on stakeholder's perspectives; and practical constraints in accessing stakeholders not being a significant concern. As stakeholder perspectives were one of four sources of data/ angles of vision on the current study aim to develop insights and recommendations on designing a high quality equitable survivorship care system, I reasoned that fewer numbers were required than if stakeholders were the only data source.

Key stakeholders were recruited via email invitation to participate in the study (see Appendices F and G). Upon receiving signed informed consent (see Appendix H) and demographic data (see Appendix I) telephone or face-to-face semi-structured/open ended interviews were conducted with the stakeholders to understand their perspectives on the current and desired state of cancer survivorship care in Canada, as well as suggestions to minimize disparities and improve equitable access to high quality cancer survivorship care for all.

The semi-structured interview guide (see Appendix J) included the open-ended questions used to probe stakeholders' perspectives on what equitable high quality care ought to look like in Canada, to what degree this goal is being achieved, and why we may/may not currently be

achieving this goal. Insights into what “kinds of people”/groups are and are not receiving equitable high quality survivorship care and why this might be so were explored with stakeholders during interviews. Further, sensitized by an intersectional lens, historical, political, social, economic and personal perspectives on stakeholders’ experiences in developing and enacting survivorship models and resources (or enacting particular survivorship practitioner roles) and the barriers and enablers they identified in achieving these goals were explored.

Interviews were digitally recorded and transcribed verbatim. Identifying information was removed and transcripts were labeled with a non-identifying signifier. A master list matching non-identifying signifiers and participant names was kept in a locked drawer that could only be accessed by the doctoral student researcher and supervisor and separate from the transcripts. Participants were advised that they could withdraw from the study at any time, and any part of the digital recording/transcript could be erased upon request.

3.3.5 Entering the field. Participants’ rights were protected by ethical review and approval prior to the study being conducted, by obtaining participants’ informed written consent prior to the interview and process consent (e.g. permission to digitally record, offer to erase parts of recording) at points throughout the interview process. Participants were offered an opportunity to review transcripts and/or preliminary data analysis. Confidentiality was maintained by removing names and identifiers within transcripts and field notes, limiting access to the data to the researcher, supervisor and dissertation committee members, and storing digital recordings and transcripts in a secure, locked drawer or electronic file for seven years, after which they will be destroyed, as per UBC Behavioral Research Ethics Board requirements.

Potential survivor participants were recruited through electronic and hard copy posters in public and private spaces around the Lower Mainland and throughout the province. Potential survivor participants contacted the researcher via email or telephone to indicate willingness to

participate in the study. An email was sent to those survivors contacting the researcher; it included the Letter of Invitation and Consent Form. Once survivors consented to participate, an interview date was mutually set and they were sent the interview guide along with a message explaining that they would be welcome, for any reason, to decline participation or ask questions, before moving forward with the interview.

Key stakeholders were recruited directly via email that included an overview of the study and general invitation to participate. Those indicating a desire to participate then received via email a Letter of Information, Consent Form and a message indicating the opportunity to decline participation and/or ask question prior to proceeding with participation. The face-to-face or telephone interviews were set up at a time and place of the stakeholders' convenience.

3.3.6 Data collection and analysis strategy. To enable the various sources of data to influence and build upon each other, the following strategy for data collection was envisioned, with the associated rationale and timeline. Each of these sources of data brought an alternate angle of vision on the phenomenon of equitable high quality cancer survivorship care, which when located within the philosophic tradition of interpretive description, aids in uncovering “more probable truths” (Johnson, 1996; Kikuchi & Simmons, 1996; Thorne, 2008b).

Three interconnected and iterative phases were conducted in the study. The first phase included beginning the secondary analysis of a subset of the CCC database as well as beginning the critical textual analysis of key survivorship documents. The CCC database secondary analysis was understood not only to offer insight into communication challenges and helpful strategies in the transition from the end of primary treatment to survivorship care, but findings from this analysis might also provide some input into the interview guide for survivorship and stakeholder interviews. The critical textual analysis of survivorship documents was understood to offer insight into the contextual and structural factors within which cancer survivorship care is enacted.

Findings from this textual analysis would therefore also inform the ongoing development of survivor and key stakeholder interview guides.

Once a significant proportion of phase one activities had been completed to inform a beginning survivor interview guide, phase two began. Phase two included survivor interviews, which continued through to the conclusion of phase three. Phase three stakeholder interviews began toward the end of phase two, once the preliminary analysis of survivor interviews was sufficiently underway to have informed the beginning stakeholder interview guide. It was anticipated that themes and patterns generated from survivor interviews would be useful to explore with stakeholders in terms of how survivorship models of care and resources might be optimized to be inclusive of these themes and patterns. Conversely, I anticipated it might be useful to explore themes and patterns identified in the stakeholder interviews with survivors. Thus, some overlap between the survivor and stakeholder interviews was intentionally built into the design plan.

3.3.7 Constructing the data. The product of data analysis within an interpretive description study is to “advance the initial description toward abstracted interpretations that will illuminate the phenomenon under investigation in a new and meaningful manner” (Thorne et al., 2004, p. 5). Data collection and analysis strategies are concurrent, including constant comparative analysis and documenting analytic thinking to provide an audit trail making explicit the logic in how the data is fractured and re-built into an interpretive description (Thorne, 2004; 2008; 2016).

3.3.7.1 Critical textual analysis: Survivorship documents. The purpose of critically examining the survivorship documentary sources was to uncover metanarratives, ideologies, beliefs, values and biases to inform the survivor and stakeholder interview guides. This analysis also aided in shining a light on some of the factors that may promote and/or detract from achieving equitable high quality cancer survivorship care for individuals and aggregates.

A poststructural deconstruction⁴⁹ approach was used to analyze a sample of survivorship documentary sources. This approach to analysis examined cancer survivorship care models, resources and systems within political, social, scientific, and historical contexts and structures, aiming to expose and disarm power relations and fragment metanarratives through making gaps and inconsistencies apparent (Derrida, 1974; Dzurec, 2003; Reed, 2009; Rolfe, 2005). Keeping an end in view of how the document influences high quality equitable cancer survivorship care, a critical deconstructive analysis was recorded for each selected documentary source. After a complete read of the document to apprehend the whole, documents were read line by line exploring and exposing ideologies and metanarratives (beginning with those identified within the literature review) that may privilege and/or obscure achievement of a high quality equitable survivorship model of care, for individuals and aggregates. Sensitized by an intersectional lens, factors underpinning these ideologies and metanarratives also were explored in the critical textual analysis of survivorship documents. As each document was analyzed, consideration of how the themes, gaps and inconsistencies *across* documents also was considered and recorded. The researcher's insights and critical reflections on the document analysis were recorded to document an audit trail of thinking and decision making.

3.3.7.2 Secondary analysis: Communication in Cancer Care database. Transcripts from and within the CCC database (Thorne et al., 2014) were analyzed inductively to determine insights and perspectives on the development of equitable high quality cancer survivorship care in Canada. This database secondary analysis, along with the critical textual analysis of survivorship documents and the literature review informed the development of interview guides/trigger

⁴⁹ Poststructural deconstruction stems from an epistemology that is often considered incommensurate with the constructivist approaches to knowledge development used throughout this study. However, within a context such as nursing's disciplinary framework that espouses a pragmatic approach to knowledge development, deconstruction may be used alongside constructivist approaches for the purpose of achieving a pragmatic end.

questions for survivor and key stakeholder interviews. This database analysis was also used to extend and add additional perspectives to the survivor interview data.

3.3.7.3 Survivor and key stakeholder interviews. Transcripts from the survivor and key stakeholder interviews were analyzed in a similar fashion to the CCC database transcripts. One significant difference, however, involves the lack of context understood within a secondary database, as the researcher only has transcripts to draw upon for analysis, without the opportunity to co-create the dialogue captured in the transcripts, or field notes that include observations and reflections on the data analysis process. As such, some of the analytic maneuvers (such as bringing early tentative interpretations of the data back to key participants for their understanding and further input) are not possible with a secondary data analysis.

Thorne (2008b, 2013a, 2016) describes the process of making sense of the data within an interpretive description study as going from pieces to patterns, and from patterns to conceptual relationships. The goal of analyzing the transcripts is to understand commonalities and patterns across individuals regarding perspectives regarding utilizing, envisioning, and/or developing cancer survivorship models and resources. With this goal in mind, techniques such as constant comparative analysis, borrowed from grounded theory approaches to analysis (Glaser & Strauss, 1967)⁵⁰, were used to compare every piece of data with all others to determine every possible relationship among the data elements.

Within interpretive description, the analysis process begins with reading the transcripts to apprehend a sense of the whole, followed by coding/grouping aggregates of smaller pieces of raw data into distinct, yet broad meaning units. Caution is applied to avoid coding data too early or

⁵⁰ As interpretive description is underpinned by nursing's disciplinary epistemology and pragmatism, techniques borrowed from other qualitative methodologies such as grounded theory may be used to achieve a pragmatic end in mind (Thorne, 2008b). In this study, constant comparative analysis was not used to generate theory; rather it was used to understand relationships among data to gain insights into how to design a high quality (equitable) cancer survivorship system of care.

too narrowly in the process of analysis, so as to leave opportunities open for re-configuration of these broad meaning units as more data is analyzed and the gaze is shifted back and forth between individual cases and the whole (Thorne, 2008b). Through comparing and contrasting of data pieces, patterns among the data were identified.

An audit trail of the logic and decisional processes used to sort, organize and group data into meaningful units and patterns was recorded, offering an opportunity for ongoing reflexivity in the analysis, giving potential direction to further questioning of the data. Some examples of this critical reflection included asking questions such as: *What led the participant to respond in this manner? What am I not hearing in this data? How is this transcript similar/different to those analyzed so far? Why am I seeing certain themes in some individuals and not others?*

The analysis of the survivorship documentary sources also influenced the kinds of critical reflections and questions asked of the CCC database, survivor and key stakeholder transcripts, including, for example, how the identified metanarratives and ideologies uncovered within the documentary sources were/were not at play in these transcripts. This audit trail and explicit documentation of analysis decisional processes also acted as a mechanism to evaluate credibility of the study (Thorne, 2008b; Thorne et al., 2004).

Moving from patterns to relationships, data analysis proceeded inductively to build a coherent whole from the patterns identified in the first phase of the data analysis. A variety of strategies were used (as per Thorne, 2016) to identify the relationships among the patterns, including *confirming your bases, expanding on associations, testing relationships, capitalizing on outliers, and engaging the critic*. To challenge the researcher's interpretations of the data, *confirming your bases* included stepping back from the data to ask "What am I seeing" or "Why am I seeing that"? *Expanding on associations* involved bringing initial tentative interpretations and observations back to the participants to see if an idea rang true for them or represented a place of

departure (versus simply “member checking” to reiterate and obtain confirmation for what they originally said)⁵¹. *Testing relationships* also involved the researcher asking questions about the data that moves back between the parts and the whole. Questions such as “What piece of the puzzle am I seeing”? or “How does this piece fit with the whole?” are seen as helpful to detect strength of relationships among the data. *Capitalizing on outliers* attunes the researcher’s mind to discovering latent conceptual variables to consider later on during data analysis. By imagining conceptual outliers (i.e. potential participant scenarios not sampled but do theoretically exist) conceptualizations about relationships in the data were extended. Related to this, the “thoughtful clinician test” was applied, where expert clinicians offer critical perspectives and insights into the unfolding conceptualization and relationships in the data. Finally, *engaging the critic* was used to forcefully consider how others might interpret the data.

3.3.8 Transforming the data. In interpretive description, that which we consider “findings” is not simply reporting the credible set of patterns that emerges from your sorting procedure. Rather, findings reflect an interpretive maneuver with in which you consider what the pieces might mean, individually and in relation to one another, what various processes, structures, or schemes might illuminate about those relationships, and what order and sequence of presentation might most effectively lead the eventual reader toward a kind of knowing that was not possible prior to your study (Thorne, 2008b, p. 163).

This interpretive maneuver to transform data within the study into to a new kind of knowing involves analysis of the data to the furthest level possible beyond the raw data. According to Sandelowski and Barroso (2003), these kinds of studies offer explanations about a phenomenon that attends fully to the relevant variations within and across the data. With the current study’s

⁵¹ This strategy is not possible for secondary data analysis of the CCC database but had been envisioned with survivors and key stakeholders.

end in view – insights and recommendations regarding the design of an equitable high quality system of care for cancer survivors, which addresses needs at both an individual and aggregate level – analysis was aimed at transforming the data to describe and explain the variation at the individual and aggregate levels. Strategies to move the data beyond simple description were discussed in the previous section. Morse (1994) suggests additional cognitive strategies that the researcher may employ to transform the data; comprehending, synthesizing, theorizing and recontextualizing. Beginning with *comprehending* the context, participants and the evolving data as a whole, judgments are suspended regarding conceptualizations of findings at this point.

The next step, *synthesizing*, merges various instances or events to describe typical or composite patterns within the data. A process of sifting through the data is undertaken to distinguish insignificant elements, decontextualizing to extract common features, and generally manipulating, verifying, selecting, and revising elements/features to be considered within the analysis.

Theorizing, the third step, involves making “best guesses” about the explanations and relationships across the data. Theoretical or empirical sources may be brought in to facilitate additional questions of the data.

Finally, *recontextualizing* brings the theorized data back into the practical environment for yet another synthesis of the data. This recontextualization permits the full appreciation for the implications of the newly generated knowledge within the practice setting/to inform practice, which is the ultimate aim within an interpretive description study framed by nursing’s disciplinary epistemology and pragmatism.

Through this process of conceptual analysis, the interpretation is moved as far as is appropriate away from the raw data. The product of the interpretive description study should include, “a coherent conceptual description that taps thematic patterns and commonalities

believed to characterize the phenomenon that is being studied, and also accounts for the inevitable variations within them” (Thorne et al., 2004, p. 4).

3.3.9 Credibility indicators. Moving beyond credibility indicators such as reliability and validity, which align with the post-positivist epistemology underpinning quantitative research, interpretive description relies on other measures of quality that fit with a constructivist, qualitative epistemology (Emden & Sandelowski, 1998, 1999; Sandelowski, 1993; Thorne, 1997, 2011). Epistemological integrity, analytic logic, representative credibility, and interpretive authority have been identified by Thorne (2016) as appropriate indicators of credibility within an interpretive description study. In the current study, *epistemological integrity* was set out through a defensible line of reasoning from the assumptions about the nature of knowledge, through the research process to interpretation of the data sources and findings. *Analytic logic* represents the researcher’s explicit reasoning throughout, from the theoretical scaffold and design decisions through to the interpretive maneuvers in the analysis and findings. Generating and documenting an audit trail to document these decisions, as well as thick description in the analysis and findings was included in this study to offer the reader assurance of credibility.

Representative credibility is addressed by sampling in such a manner that aligns with the theoretical claims laid out at the start of the study (Thorne, 2016). In the current study, sampling to foster maximal variation helped to explore and explain individual variations across commonalities with regard to cancer survivorship care. Seeking multiple angles of vision and data sources (i.e. CCC database secondary analysis, survivorship document critical textual analysis, survivor interviews, stakeholder interviews, field notes) and triangulating these sources of data in the analysis in order to more closely approximate the truth claims that will be depicted in the findings was also an approach to fostering credibility.

Interpretive authority includes measures to ensure the researcher's interpretations are trustworthy, are embedded within the data and reveal some truth external to one's own bias or experience (Thorne, 2008b). Strategies such as checking the researcher's early tentative interpretations with participants, and clearly explicating a line of reasoning to explain which truth claims are individual in nature versus those representing more common truths were examples of demonstrating interpretive authority included in the current study.

In addition to the aforementioned credibility indicators, Thorne (2016) offers further measures to evaluate the product of an interpretive description study. *Moral defensibility* demands that the researcher account for the possible uses of the findings at the outset of the study. In this study, knowledge generated from the multiple data sources provided new insights and recommendations to design equitable high quality survivorship care. This study therefore had the potential to then improve access to and experience of high quality care of future survivors who engage with survivorship models of care, resources and systems that address their unique needs.

Disciplinary relevance of the study findings lies within nursing's aim to move beyond simply describing or theorizing, to addressing the "so what". Study findings offer strategies to improve cancer survivorship models of care to address the unique needs of survivors as well as aggregates. Further, nursing's social justice mandate was enacted through this study to highlight and offer strategies to begin to address inequity in cancer survivorship care.

Related to disciplinary relevance is the credibility indicator of *pragmatic obligation*, which gets at nursing's mandate for pragmatic action, rather than simply theorizing. The current study used nursing's disciplinary epistemology as the theoretical scaffolding and was underpinned by pragmatism such that the project was imbedded within the practice environment to generate practice-derived solutions and recommendations. Strategies such as maintaining an eye toward the study end in view, using multiple data sources from the practice environment to get multiple

angles of vision on the issue within the practice environment and sustaining attention to the clinical origins of the problem throughout data analysis and interpretation of findings assisted in achieving this pragmatic obligation.

Contextual awareness as a credibility indicator requires the researcher to locate new knowledge generated from a study to recognize the influence of context due to the social construction of knowledge that is influenced by time and place (Thorne, 2016). Every effort was made to fully describe and explicate the context within the study as the epistemology underpinning interpretive description holds that people are contextual beings who exist in relation to others within social, cultural, political and historical processes, and are shaped by situations, context, environment and processes (Doane & Varcoe; Rodney et al., 2013; Sewell, 1992).

Study strategies to foster contextual awareness included explicitly describing and explaining the study design choices that shape the context for the study. I used an intersectional lens in the development of interview guides and data analysis. These sensitized me to the layering of factors and contexts that shaped access to and the experience of engaging with cancer survivorship models of care and resources, as well as maintaining an awareness of the influence of context through analysis and interpretation of findings.

Probable Truth is the final credibility indicator proposed by Thorne (2016) that addresses the ongoing challenge within qualitative research that is based on an epistemology of multiple co-constructed realities. Keeping in mind that knowledge generated from an interpretive description study aims to approximate truth as closely as possible, recommendations and claims about practice based on this knowledge must be kept in check/perspective, considering the context, time and space within which the study was conducted.

3.4 Summary

In this chapter, I have set out the theoretical and methodological foundation on which the

study design was generated using a qualitative interpretive description approach. I have attempted to make explicit the ideas that played a role in envisioning the study from the outset and guiding the decisions I made to engage in this work using multiple data sources in a somewhat phased but also overlapping series of analyses toward uncovering some of the complexities that I expected to find within the topic of the study. In designing an approach that would allow me to consider the study problem from multiple angles, I hoped to be able to integrate the insights that arose in multiple contexts and ultimately generate findings that could contribute to an integrated and informed direction for developing models of cancer survivorship care that would not only meet the needs of populations, but also address the highly distinctive and complex needs of people in a manner that reflects the equity aspirations of our health care system.

CHAPTER FOUR: Findings from the Survivorship Documentary Sources

4.1 Introduction to the Findings Chapters

There is general consensus that the care of cancer survivors in Canada is suboptimal. Growing evidence of population-based health disparities reveals that those who are older, have advanced disease at diagnosis, are living remotely, have low socioeconomic status, and who identify as indigenous or ethnic minority have fewer opportunities and access to services to support optimal health after treatment for cancer. While biology may account for some of these differences in survivor health outcomes, it is not well understood how structural, contextual and other factors work together to create opportunities for health for some, and not others.

This study adds to our current understanding of cancer survivorship care by exploring and explaining how these structures, contexts and factors (i.e. social, political, historic, economic, personal), and survivor health experiences and health management strategies shape the development of and access to high quality cancer survivorship care for all. This multilayered, intersectoral approach to understanding what shapes survivorship care systems and resources helps to highlight and unravel the complex nature of the issue; and as such, aid clinicians and decisions makers to find multi-layered approaches to addressing the issue. This approach also helps to highlight how simplistic answers, such as, for example, the addition of navigator roles, may be problematic and unwittingly add to inequities.

In this study I have structured the findings to answer the research questions as well as position the findings to be taken up by clinicians and policy makers alike. I have structured the data to demonstrate the flow of logic, with data analysis occurring iteratively and shaping subsequent analysis and resultant interpretations), ultimately offering insights and recommendations to improve equitably high quality survivorship care.

Drawing on four sources of data across three phases, this study involved: (Phase 1) critical textual analysis of survivorship documentary resources (e.g. guidelines, policies, etc.); (Phase 2) a secondary analysis of a survivorship subset of the Communication in Cancer Care database; and (Phase 3) survivor and stakeholder one-on-one interviews.

To build a foundation for entering into data collection and interpretation in Phase 3, I first summarized Phase 1 and 2 findings. The documentary sources provided a lens through which to view current challenges, gaps and inconsistencies as well as opportunities to identify and strengthen aspects of survivorship care to move toward equity and high quality. The secondary analysis of the Communication in Cancer Care database subset (Thorne et al., 2014) offers insights into the experiences of the transition from end of primary treatment to survivorship care and provided direction for key areas to explore within Phase 3 (interviews with survivorship and stakeholders).

I begin describing Phase 3 findings by grounding the reader in the gap that survivors described (and stakeholders observed) between their expected and actual survivorship care experiences. This provides an entry point into some of the key problematic issues and unmet needs experienced by survivors that may be a result of and/or impacted by the system and other structural and contextual factors. It is the gap between expected and actual survivorship care that creates the need to look further into why this gap exists, what shapes it and what we may do about it.

To demonstrate that the gap in care experiences and outcomes is experienced differently at both the individual and group levels, I describe each separately. Strategies and implications for addressing this gap at each level are slightly different. Also, by presenting the findings in this way, I hope that the insights arising from this analysis can help clinicians and decision makers to

better design optimal survivorship care models and resources that consider care at both the individual and group level.

Once the gap is explicated at individual and group levels, I present findings that describe and explain, at the system level (i.e. structures, contexts, factors within the system), why and how this gap may be shaped and perpetuated. I describe barriers and strengths within the system to promote equitably high quality care, offering clinicians and decision makers opportunities to manipulate these barriers and strengths to optimize survivorship care. An intersectional lens was used in this study as I did not expect that all system level factors would fit neatly into a binary “either/or” reporting structure of barriers and strengths. Where appropriate, I used direct quotes from the data to show the layering and intersection of various factors, contexts and structures at the system level to emphasize the complexity of the issue. I also attempted to construct from the data possible solutions (or at least ways of thinking about solutions) to these complex challenges. Tensions among and between factors, contexts and structures (e.g. between evidence-based medicine and person centred care) are also explained as they contribute/challenge high quality survivorship care for all.

Finally, I offer recommendations to improve survivorship care systems and resources to deliver equitably high quality care. The recommendations are structured within two levels:

1. Direct recommendations from survivors and stakeholders (from Phase 3 interviews). These findings are organized to offer overarching/conceptual recommendations, as well as those aimed at the individual, group and system level.
2. Following this first layer of recommendations, I synthesize and integrate data from other sources (e.g. critical documentary analysis; from earlier in phase 3, such as strategies and approaches to address barriers and promote strengths; etc.). This

integration and synthesis moves the analysis further away from the raw data, and toward interpretation.

4.2 Introduction to Phase 1

To lay the foundation for this study, in Phase 1, I conducted a critical textual analysis of survivorship documents to gain insights into how the survivorship challenge has been taken up across documents that inform practice, education and research related to cancer survivorship in Canada. Through analysis of these documents I offer a reflection of how society views and has responded to the survivorship challenge. This analysis also offers a lens to view current challenges, gaps and inconsistencies as well as opportunities to identify and strengthen aspects of survivorship care to move toward equity and high quality. In particular, I have kept in view how these documentary sources address the population of survivors with unmet needs as a result of treatment and care, throughout this analysis.

In Phase 1 findings, I begin by broadly describing the survivorship documentary sources reviewed. On the basis of this review and critical analysis across the collection of documentary sources, a number of key themes stood out as important to highlight as they relate to equity and high quality survivorship care. I explore each of these themes in detail to critically reflect on how they may impact equity and high quality survivorship care.

4.3 Documentary Sources Description

There was no single overarching document that I could locate that provided a high level overview of cancer survivorship care (current and/or envisioned) in Canada. Given this, a diversity of documents were purposefully selected for analysis, to provide a broad perspective on how cancer survivorship has been positioned by clinicians, educators, researchers, policy makers, leaders, and others informing cancer survivorship care. These documents were assembled through my knowledge of key survivorship documents, reviews of key websites (e.g. the Canadian

Partnership Against Cancer (CPAC), Canadian Cancer Society (CCS), Canadian Association of Psychosocial Oncology (CAPO), major cancer treatment centres, survivorship programs (publicly funded and not-for-profit), survivor advocacy organizations, research funding organizations], and recommendations from key stakeholders including those interviewed in phase 3 of this study. The majority of these documents were identified and analyzed prior to proceeding through phases 2 and 3 of this study (see Figure 1). However, a few new documentary sources were identified by key stakeholders in phase 3 of the study, and were included in a final analysis of phase 1. These new documentary sources did not shift the content or add new themes to the analysis of phase 1; rather they added depth and validation to the themes that already had been identified.

Over 70 survivorship documentary sources were reviewed including survivorship clinical practice guidelines, symptom management guidelines, survivorship care plans, position statements, policies, frameworks, survivorship programs and resources, national survivorship initiatives, key reports and discussion papers, workshop proceedings, toolkits, and research grant structures (see Appendix K). Although a wide range of documents were reviewed, the majority of these documents included those informing practice (e.g. clinical practice guidelines, survivorship care plans), and key higher-level reports and discussion papers, most of which were generated from the Canadian Partnership Against Cancer (CPAC), which is Canada's national cancer control strategy organization. The reports and discussion papers covered a wide range of topics, such as national cancer control strategic plans, workshop proceedings and system performance reports on disparities in cancer care, updates on advances in national survivorship care initiatives and investments made in survivorship research in Canada.

Most of the documents analyzed were Canadian in origin. Some American clinical practice guidelines were included in the analysis, as they often provide direction to survivorship care in Canada, in the absence of Canadian-developed guidelines (see for example, Resnick et al., 2015).

Documents specific to cancer survivorship care in British Columbia, such as for example, British Columbia Patient-Centred Care Framework (British Columbia Ministry of Health, 2015b) also were targeted, to align geographically with the survivors included in phase 3 of this study.

4.4 Survivorship Documentary Sources: What Can They Tell Us About this Evolving Field?

On the basis of my analysis across the collection of documentary sources that contribute to our understanding of the issues of equity and high quality survivorship care, I came to appreciate that these documents are characterized by extensive variability in the use of terms such as *survivorship*, and the ideas that they signify. This extreme terminological variability makes it difficult to discern a coherent thrust to the overall body of material.

Additionally, I found the terminological fluidity and interchangeable use of *patient-* and *person-* centred care definitions and concepts to be concerning, as their unique underpinning elements are different. Each of these terminological uses creates different foundations upon which to build survivorship models of care and resources that may or may not promote equity and high quality survivorship care. I also noted that the body of material was focused far more on matters at the population and system level than with what the survivorship experience entails at an individual person-focused level.

Woven throughout these three broad areas of insight (definitional variability, fluidity between patient-and person- centred care, and population- and system- dominance), I also was struck by the invisibility of equity concerns. Across the 70+ documentary sources reviewed for this study, I found that only five included explicit language on the social determinants of health (SDH) or other contextual or structural factors that may contribute to inequity among cancer survivors. When equity language was explicitly included, it was often limited to a population focus on enhancing access to care, or in relation to collecting SDH data (e.g. SES, education, income) to describe inequities among populations or between groups. Language about how the SDHs shape

opportunities for survivorship and/or optimal health for individual survivors was not articulated in most documents, which made me curious about how equity and high quality survivorship care can be achieved without structures or direction to include equity principles and equity-informed approaches.

These three broad areas of insight (definitional variability, fluidity between patient- and person- centred care, and population- and system dominance) derived from critical review of the documents frame the presentation of my findings, based on the analysis of relevant documentary sources for cancer survivorship in the current context. I include a discussion of equity concerns, woven throughout my analysis in relation to these broad areas of insight.

4.4.1 Terminological fluidity: Survivorship. A major issue that I encountered when conducting a comparative analysis across documents was the variability and fluidity in how the terms *survivor/ship* and *person-centred care* were defined, interpreted and taken up into survivorship practice. While the majority of documents pointed to the centrality of these terms/concepts as foundations for high quality survivorship care, there was little obvious agreement across documents as to what survivor/ship and person-centred care should entail. I begin by illustrating the nature of these variations, and demonstrate how these variations may potentially influence or challenge equity and high quality survivorship care.

The most striking inconsistency across documents that I noted was the fluidity and variability with which the term *survivor/ship*⁵² was used. Within and across documents, the terms *survivor*

⁵² As noted in the introduction to this study, the definitions of *survivor/ship* are variable in the literature. While most experts would agree that *survivorship* constitutes a distinct phase in the cancer trajectory, beginning at the end of primary cancer treatment and continuing to the end of one's life (Hewitt, Greenfield, & Stovall, 2006; Rowland, Hewitt & Ganz, 2006), there is little consensus among them in the use of the term *survivor*. Differing perspectives and definitions of the term *survivor* among advocacy groups, organizations, care delivery services, funding bodies, and survivors themselves highlights how the term is constructed by historical, biomedical, social, political, cultural and personal forces (Bell, 2010,

and *survivorship* were used interchangeably, with *survivorship* used most commonly. The term *follow-up care* was also used synonymously with *survivorship* in some cases to denote care required after primary treatment ends.

In general, I noted three overarching types of documents depending on how narrowly or broadly *survivor/ship* was defined and taken up. In its broadest definition, generally represented in documents providing perspectives from national cancer control organizations, advocacy groups and community based survivorship programs, survivor/ship was defined as beginning at diagnosis and continuing for the remainder of one's life (see for example, Canadian Partnership Against Cancer (CPAC), 2012a; Ristovski-Slijepcevic, 2008; Ristovski-Slijepcevic & Bennie, 2008; Rock et al., 2012; University Health Network (UHN), n.d.]. A middle ground definition noted across many documents identified survivorship beginning at the end of primary treatment and lasting until recurrence or the remainder of one's life (see for example, Howell et al., 2011; Sussman et al., 2016; Resnick et al., 2015). This mid-range definition was reflected in documents supporting clinical services, such as guidelines, survivorship care plans and model of care recommendations. The narrowest definition of *survivor/ship* was found in documents specifically focusing on survivorship programs and resources, targeting the transition period between active treatment and primary care (see for example, Chomik, 2010; Ward, Doll, Ristovski-Slijepcevic, Kazanjian & Golant, 2010)].

With the challenge of equity and high quality survivorship care in focus, I was curious to explore and understand how the definitional variability across survivorship documents, as it relates to this current study, may have potential unintended negative impacts. A key issue that stood out to me across all three survivorship definitional groupings was the layering of curative

2012; Doyle, 2008; Feuerstein, 2007a, 2007b; Khan, Rose, & Evans, 2012; Malin, 2011; Peck, 2008; Sulik, 2013).

versus non-curative disease pathways, and the implications this had on defining who is a survivor. For example, many documents specifically identified a survivor as an individual who is receiving/has received curative treatment for their cancer, narrowing the definition to serve a potential sub-group of survivors. Conversely, other definitions broadly included all survivors regardless of their disease status. I did not observe, however, a similar layering of survivor/ship definitions in relation to other elements, such as any of the documented ongoing unmet needs of cancer survivors (e.g. practical, emotional, spiritual, social, informational). I hypothesize that this foregrounding of one's disease status within survivor/ship definitions, without consideration of other aspects of the survivorship experience, may be a potential barrier to achieving person-centred care (which is inclusive of all needs, not just those related to disease status). As such, there may be reciprocal implications as a result of the definitional fluidity in survivors/ship and person-centred care.

4.4.1.1 Broad definitions: Everyone is a survivor. Although the intent of very broad definitions of survivor/ship, where everyone is a cancer survivor from diagnosis onward, may be intended to be as inclusive as possible, there are also drawbacks. For example, in its broadest definition, it is difficult to filter out survivors who are managing well, from those with explicit unmet needs who require ongoing support. As a result, designing models of care and resources for survivors in this broad category may be unnecessarily complicated and may not support the alignment of publicly funded health care resources to those survivors who really need it. This broad definition also may not be sensitive enough to sort out “cancer-related” needs from ongoing health promotion or other chronic illness-related needs, challenging survivorship programs and resources to optimize their impact.

From an equity perspective, when survivorship definitions are broad, and everyone's needs are seen as equal, there is a potential for contextual factors to inadvertently shape whose needs are

deemed a priority. For example, survivors with more minor needs (and/or who have the capacity to self-manage their needs), and who do not experience marginalizing conditions within society (e.g. have higher education, adequate financial and social support) may have greater opportunity to advocate for allocation of resources and programs that meet their need. This is compared to those survivors with complex, ongoing needs and without similar capacity or opportunities to advocate to have these needs met, due to marginalizing conditions within society (e.g. racism, rural/remote location, limited literacy, poverty, lack of social support). Broad definitions of survivorship therefore may have the potential to further dilute or silence the needs of subgroups of survivors with complex situations and needs. Rather than prioritization and alignment of survivorship programs and services based on complexity of unmet needs (and/or limited capacity to self-manage these needs), broad survivorship definitions may create opportunities for those with the greatest capacity to advocate for their unmet needs, regardless of complexity or self-care capacity, to have programs and services aligned to these needs. In a publicly funded cancer care system with limited resources, this may potentiate inequities.

Similar tensions may play out between various sub-groups of survivors in these broad survivorship definitions, such as between those with curative and non-curative disease. As I mentioned earlier, I noted an intriguing tendency across many documents to offer a binary perspective of survivors with either curative or non-curative disease, indicating an artificial separation between these sub-groups of survivors. This is somewhat surprising, given the rapid advances in cancer treatment over the past 5-10 years, blurring the lines between those “cured” and living as a survivor, and those survivors living decades with stable yet metastatic (i.e. non-curative) disease. Adding to this complexity, are new palliative and supportive care treatments that extend individuals’ quality and length of life, even when they are at their end of life with incurable disease. In defining survivorship in the broadest sense, all of these subgroups are

considered survivors. As a result, designing models of care and alignment of limited public funds and resources for such a broad group of survivors with diverse needs is very complex, and may create tensions that result in inequities between the various sub-groups.

In these current, early phases of cancer survivorship system development in Canada, I anticipate that the carry-over effects of the predominantly disease-focused cancer treatment system into survivorship may negatively impact individuals with non-curative disease, especially when definitions of survivorship are broad. Without a solid foundation in place for survivorship models and resources that address a range of individuals' holistic needs (i.e. not just disease status), I suspect the default strategy may be to prioritize the needs of survivors receiving curative treatment, as systems are already in place in the treatment setting that may carry over into the somewhat blurred lines between treatment and survivorship.

Within the cancer treatment system, I see many contextual factors that are already at play to reinforce this somewhat invisible and taken-for-granted privileging of individuals with curative cancers. For example, the biomedical-driven cancer treatment system, underpinned by evidence-based medicine, equates the highest levels of success with cure ((Bell, 2010; Bell, 2012). In turn, cancer treatment systems and resources are generally structured to optimize cure, and/or length of life. Societal metanarratives about cancer, equating victory with transformation as a result of having had or lived through cancer (Bell, 2013; Maliski, Heilemann, & McCorkle, 2002), also adds to the focus on leaving cancer behind, rather than living with it. These factors, intersected with efficiency drivers to optimize seamless movement through the cancer system, all may play a role in prioritizing and addressing the needs of survivors with curative disease above others, especially when definitions are broad and there is blurring of lines between “treatment” and “survivorship” care.

4.4.1.2 Narrow definitions: Focus on transitions. Not surprisingly, I also noted this tendency to privilege individuals receiving curative treatment within the collection of documents reviewed that used a very narrow definition of survivorship. Many of these narrow survivorship definitions were associated with guidelines, programs and resources to manage the transition between the end of primary treatment and return to primary care, largely for survivors who had received curative treatment (see for example, American Society of Clinical Oncology (ASCO), n.d.; Khatcheressian et al., 2013; Sussman et al., 2016). As I reflected on this observation, I wondered what are the implications for those individuals who do not fit into this “curative treatment” category in terms of equitable opportunities for support and care to have “survivorship” needs met? Clearly those who receive curative treatment require support to transition back to primary care to have their disease-related and holistic needs met post treatment. However, this narrow survivorship definition generally does not address similar disease-related and holistic needs of those who were unable to receive curative treatment. This excludes a large group of individuals who may otherwise be considered “survivors”, such as those who do not have curative disease, require long term maintenance treatment, are receiving treatment that does not have an “end”, and/or are experiencing social, financial, geographical, psychological or other barriers preventing them from undertaking curative treatment. Based on these observations and reflections, I anticipate that the binary positioning of individuals receiving curative treatment versus “all others”, and the tendency to prioritize the needs of those receiving curative treatment, may create inequities between groups within these current narrowly defined survivorship definitions.

In general, I found it concerning that a definition of survivorship was tied so narrowly to a transition across care settings, especially when there is mounting evidence that suggests, from survivors’ perspectives, that their survivorship-related needs may last a lifetime (Ganz, 2009; Hewitt et al., 2006). It is important to reflect on why and how these narrow survivorship

definitions may have come into play, as it may help to uncover some key factors shaping survivorship care models and resources and provide insights into survivorship definitional fluidity. Important questions remain, including: Why is it important to have survivorship definitions that are tied to managing transitions between cancer treatment and primary care settings? Whose needs or purposes does this narrow definition serve and who does it leave out?

In my review of the survivorship documents focusing on cancer transitions, I noted three concepts that were commonly mentioned or eluded to: economic efficiency, optimizing primary care, and survivor self-management. I was curious to explore and understand how these factors may work together to create survivorship definitions narrowly tied to transitions in care and how they collectively may influence high quality and equity in survivorship care.

From an efficiency perspective, narrow definitions of survivorship may be an effective mechanism to move survivors who no longer need treatment-related support from the speciality cancer treatment system, back to primary care, with support to self-manage their ongoing needs. In this way, the narrow definition of survivorship may optimize efficient use of the health care system (at least from the perspective of the specialized cancer treatment system) for a subset of survivors. However, the primary care system and primary care providers within in may not have the capacity to address the complexity of cancer survivorship needs post-treatment, even for this narrow definitional subset of survivors who have received curative treatment.

Within a number of reports and discussion papers reviewed for this study, I observed a growing dialogue, and related tensions among oncologists and primary care providers (PCPs), as to where survivors are best cared for post treatment completion (see for example, British Columbia Ministry of Health, 2015a, 2015b; Chomik, 2010; Sussman et al., 2012). These tensions may reflect the somewhat obscure/hidden power relations between systems and between care providers which also may influence this narrow definition of survivorship. For example,

within a number of the documentary sources reviewed, a growing cadre of willing PCPs with knowledge and capacity to care for subsets of survivors in the primary care setting was sometimes met with resistance by oncologists in the specialty cancer treatment system. These oncologists expressed lack of trust in PCPs and were reluctant to “discharge” survivors back to primary care. Conversely, PCPs expressed frustration at oncologists and/or the cancer treatment system for not communicating essential information required to effectively care for survivors who had transitioned back to primary care. Stepping back and reflecting, I found it curious that this dialogue about transitions in care largely focused on the structures and processes required to manage these tensions and gaps between health professionals and systems, rather than on survivors’ needs and preferences. Further, although survivor self-management was emphasized as an important goal throughout many of the “transitions-focused” documents, I was surprised to find little discussion about strategies to support survivors to self manage their survivorship needs. With these challenges noted, opportunities for person-centred care during these narrowly defined survivorship transitions may be limited.

The emergence of survivorship care plans is an example of a resource that was developed with the intention to improve survivors’ continuity, self-management and person-centred care, particularly during the transition between specialty oncology and primary care settings (see for example, American Society of Clinical Oncology (ASCO), n.d.; OncoLink at Penn Medicine, n.d.]. Yet upon a close read of various survivorship care plan documents, I found myself wondering where and when survivors’ perspectives and needs were included in these documents. Instead, these SPC’s appeared to be structured as a communication tool between oncologists and primary care providers regarding treatment summary and disease-surveillance recommendations.

I wonder to what degree these tensions and power relations between and within systems and care providers have effectively created an artificial spotlight on the needs of the system and care

providers, thereby obscuring what should be the real focus – survivors needs, from the survivors’ perspective. Going forward, I also wonder what effects these system and care provider tensions and the power relations that surface in this transition between specialty and primary care may have on the ability to deliver on person-centred survivorship care across all definitions.

4.4.1.3 Mid-range definitions: Survivorship starts after treatment. Given the aforementioned challenges inherent in both the broad and narrow definitions of survivorship, I was curious to understand how the mid-range survivorship definition noted across documents reviewed may shape the development of survivorship systems, models and resources. This mid-range definition, “survivorship begins at the end of primary treatment and lasts until recurrence and/or for the remainder of one’s life” see for example, (Howell et al., 2011; Resnick et al., 2015; Sussman et al., 2016), may attempt to promote equity in that the definition leaves the door open to be inclusive of most survivors, once their treatment is completed, regardless of whether their cancer is curative/non-curative. However, as identified earlier, this mid-range definition may also pose challenges to deciphering between individuals with complex ongoing needs and those who may be managing well post treatment.

Despite being inclusive of individuals with curative and non-curative disease, another interesting pattern that I noted within the mid-range survivorship definitions was the volume of documents that specifically focused on survivors with curative types of cancer (e.g. breast, prostate, lymphoma), versus other cancer types where cure is less common (e.g. pancreas, brain). For example, multiple survivorship clinical guidelines are available to guide survivorship model of care development specifically for survivors with these curative types of cancers (see for example, Cancer Care Ontario, n.d.; Runowicz et al., 2016). While it is not surprising to find more guidelines available for curative types of cancer (which in these early stages of survivorship care development, may have more research evidence to support the existence of a survivorship

guideline), I am concerned about the impact on development of equitable survivorship care for all. In the absence of currently available high-level evidence to drive clinical guidelines for less curable types of cancer, special attention must be paid to equity when evolving survivorship models of care. Without an equity lens in place, the default strategy in an evidence-based medicine-driven culture may be to develop survivorship programs only for those cancers with guidelines. I see this pattern already being established in some survivorship programs across the country that only include populations for which guidelines are available (see for example, The Ottawa Hospital, n.d.)

Another interesting pattern in this category of mid-range survivorship definitions is how the “typical” cancer trajectory formed the foundation for its definitional boundaries; that is, an individual is diagnosed with cancer, has treatment, and when the treatment is complete, they are considered a survivor. This normative trajectory may not necessarily represent everyone, and may exclude some subgroups. I wonder, for example, about the subgroup of individuals who do not receive “treatment” (e.g. prostate patients on watchful waiting or active surveillance programs, individuals who decline conventional treatment), and whether or not these subgroups may not be included as “survivors” in this mid-range definition. It would make sense to include these individuals, as they likely have many similar ongoing needs as those who might fit the normative cancer trajectory, such as psychosocial issues (e.g. fear of recurrence and/or living with minimally detectable, low levels of slow growing disease), symptom management, financial challenges, and disease surveillance/monitoring.

I was intrigued by the tendency within all definitional categories, especially the narrow and mid-range definitions, to be so closely tied to/grounded in temporal aspects of the disease-focused cancer trajectory. For example, with respect to the mid-range survivorship definition, survivorship is located in relation to having completed treatment. While this location of

survivorship in relation to having completed treatment may have benefits with the currently constructed cancer *treatment* system (i.e. the treatment system is designed to treat and does not have capacity for ongoing survivorship care for all), I wonder how it aligns with person-centred care principles and goals. From the survivors' perspective, does this cancer trajectory-based organization of survivorship care and services optimize their ability to identify and have their needs met? If this organization of services does not optimally address survivors' needs, how should we re-think this organization to encourage person-centred care approaches to survivorship? How should we balance survivors' needs with the current structure and capacity of the cancer treatment and primary care systems? Does this "post-treatment" organization of services cater to some subgroups of survivors but not others? These questions will be important to consider moving through analyses in Phases 2 and 3 of this study.

4.4.1.4 Survivorship and palliative care? A final issue worthy of discussion that I noted while exploring survivorship definitional fluidity was the positioning of palliative care⁵³ concepts in relation to survivorship. Across most survivorship documents reviewed, palliative care language was either absent, or vaguely alluded to. For example, within the majority of the documents utilizing broad and mid-range definitions, many of which included individuals with non-curative disease, survivorship is described as lasting "for the remainder of one's life". I interpreted this open-ended definition to suggest that palliative care may be included in

⁵³ Palliative care definitions commonly focus on the relief of suffering and improvement of quality of life for people living with advanced illness (Canadian Hospice Palliative Care Association, n.d.). It is also described as an approach to life threatening illness, applicable in the early phases of illness, in conjunction with other therapies that are intended to prolong life (World Health Organization, 2012). While early definitions included only those with incurable disease, modern definitions aim to include individuals where cure may be unlikely, but not impossible (Hawley, 2014). Across most palliative care definitions, the focus is not only on disease management, but also in meeting the holistic needs of patients and their families. Palliative care often is used synonymously with supportive care, especially when integrating early in the cancer trajectory, to avoid associations of the term palliative care with dying (Bruera & Hui, 2010).

survivorship definitions, as at some point, as their disease progresses, most cancer survivors will require support to optimize their quality of life.

This fuzziness about where palliative care sits in relation to survivorship may reflect, at least in part, the changing disease trajectory of cancer, where growing numbers of individuals are living longer with metastatic, yet mostly stable cancers (e.g. women with Her2 positive metastatic breast cancer, people receiving personalized oncogenomic treatments that prolong the lives of those with incurable cancers). This new generation of “survivors” who are living extended periods with metastatic/non-curable cancer is pushing the traditional boundaries of survivorship definitions, which typically/historically included only those with curative disease or prolonged remission. Similar challenges are noted in the evolution of palliative care definitions, which continue to shift in response to new evidence supporting the benefits of early integration of palliative care (Hawley, 2014). I anticipate that over time new cancer treatments, including those palliative medical and supportive care treatments that extend life without achieving a cure, will further blur the lines between survivorship and palliative care.

These blurred lines raise many questions and may pose challenges when allocating resources and/or designing survivorship models of care. For example, can one be a survivor and receive palliative care? If so, at what point does one leave the survivorship care system, and enter the palliative care system? Are these two systems separate, or is there overlap and/or integration between the two? If the survivorship phase lasts until the end of one’s life, when and how should palliative care teams be integrated to address survivors’ needs? Is the transition between survivorship and palliative care systems fraught with similar tensions, power struggles and gaps as the transition between end of treatment and primary care? If so, how can a person-centred focus be maintained, rather than a focus on the needs of the system and/or care providers? These and other questions will need to be sorted out to effectively align survivorship resources with

those who have complex ongoing “survivorship” needs. Without this clarity, there is the real possibility of resources from survivorship being pulled into palliative care, where needs are often complex and the demand for services is high.

4.4.2 Person- or patient-centred care? In the context of the previous observations, I identified some challenges that survivorship definitional fluidity may pose to achieving person-centred care. Adding to these *survivorship* definitional challenges, I also noted that the concept of *person-centred care* itself was inconsistently mentioned, and when it was, it was variably defined, taken up and measured across the documents reviewed. One of the most interesting and concerning disjunctures that I noted was the variation in and interchangeable use of the terms *patient-* versus *person-* centred care. Although the terms seem similar, I believe the definitional differences are critical to understand and untangle, as the blurring of these definitions and their unique underpinning elements have the potential to promote inequities and under-deliver on high quality care.

To illustrate these concerns for equity and quality regarding the variation in use of these terms, I begin by clarifying the definitional differences between *patient-* and *person-*centred care, and the key elements underpinning each of these definitions, based on current published literature.⁵⁴ I

⁵⁴ Prior to entering into the analysis of these phase 1 findings, I did not fully appreciate the distinction between *person-* and *patient-*centred care. It is likely that most of the survivorship documentary source authors may not have appreciated these distinctions either, as reflected in the extreme variation across documents in the use of these terms and key elements underpinning these terms. I became quite curious as a result of this observation of definitional fuzziness and fluidity, and, in order to follow a thread of critical reflection across these definitions, I made the decision to go back to the literature to find a common perspective on *person-* versus *patient-*centred care. I fully appreciate that this approach is somewhat unconventional in that I have briefly returned to the literature to bring in an interpretive lens during this analysis (rather than reporting the findings and then discussing them interpretively). However, this brief return to the literature is only for the purpose of gaining perspective on the distinction between *patient-* versus *person-*centred care, which was impossible to achieve with the language choices within the documentary sources alone.

then explore and explain how the language and messaging within the survivorship documentary sources reviewed aligns and/or departs from these key elements, including an analysis of how this may impact equity and high quality survivorship care going forward.

As a starting place to illuminate the differences, a recently published person-centred care guideline reviewed for this study very deliberately clarified that “Person-centred care is the evolution of patient-centred care, a nominal shift that signals to the system the profound importance of being treated as a person first, and as a patient second” (Bidy et al., 2015, p. 3). I interpreted this clarification in *person* versus *patient* definitions to signal a very important shift in how we ought to know and locate individuals within the broader context of health and illness, and within the health care system. Despite this beginning point of clarity set out in this person-centred care guideline, the majority of the remaining survivorship documentary sources reviewed were extremely entangled and fuzzy with respect to delineating *person-* versus *patient-*centred care. Therefore, I believe an important place to begin untangling *person-* versus *patient-*centred care is to return to the literature to gain perspective on the definitional differences. Ongoing challenges inherent in the older, *patient-*centred care definitions and approaches, related to equity and high quality survivorship care, are also highlighted. I also describe key elements of *person-*centred care that are essential to embrace in order to achieve equitably high quality survivorship care.

4.4.2.1 Patient-centred care perspective. This is a somewhat older term that is aligned with biomedical models and systems assigns individuals a predetermined role (i.e., the “patient”) and places them within the health care system according to their disease-driven needs (Starfield, 2011). In the context of survivorship, this perspective of survivor as “patient” encourages a dominant focus on physical needs, such as disease surveillance, late and long-term effects management. This perspective also requires individuals to fit into the already structured and siloed health care system that caters to these physical needs, with little attention to survivors’

unique, holistic and individual needs. *Patient*-centred care commonly refers to interactions within visits or episodes of care focusing on one's disease, rather than developing interrelationships over time to better understand the person (Starfield, 2011). Without accumulated knowledge of the person over time, it is difficult to anticipate individual vulnerabilities and areas of resilience to optimally plan for care that maximizes individuals' self-care capacity, which is an element of high quality care.

An individual's input into their care is included in a *patient*-centred perspective. This input, however, is often limited to a pre-determined range of choices, aimed at the general population, focused on biomedical needs, rather than based on the individual's unique, holistic needs. Additionally, rarely is any attention paid to the structures and contexts that shape an individuals' ability to achieve and maintain health (e.g. social determinants of health, policy, racialization), thereby limiting opportunities for individualized, holistic care (Starfield, 2011; van Mossel, Alford & Watson, 2011). Opportunities to consider the structures and contexts that might create inequities (e.g. policy, models of care) also are not included in a *patient*-centred perspective.

I believe that the assigned "patient role" in *patient* centred-care generally also carries with it inherent power inequities in relation to other health professionals and the health care system, and that assigning a patient role, inadvertently disempowers individuals from the outset. Combined with a limited range of biomedical-focused choices offered by the health care system that are common to the general population of survivors, and lack of relationship with health care providers over time, this disempowered assigned patient role can undermine an individual's capacity to maximize their self-care agency and to self-manage the holistic survivorship care needs that are most important to them.

4.4.2.2 *The newer person-centred perspective.* This approach encourages health care providers to know the person first, including their beliefs, values and goals, so that survivorship

care can be modified to the individual's context and to address needs that are most important to that individual (Bidy et al., 2015; Sharma, Bamford & Dodman, 2015; Starfield, 2011). Using a *person-centred* perspective, health care systems, models of care and resources ought to be designed around these individualized and unique contexts that are inclusive of individuals' full range of needs (e.g., physical, emotional, practical, psychological, social, spiritual). Although biomedical/physical needs are apparent in this *person-centred* perspective, they do not drive or primarily dominate the care interactions or model of care design, as in the older, *patient-centred* perspective. Relational care is an important component of *person-centred* care, where the relationships developed among the individual and their health care team over time are a considered a critical vehicle through which to know the person first, so that their care can be designed around what matters most to them (Kitson, Marshall, Bassett & Zeitz, 2013; van Mossel et al., 2011). I believe this relational care approach that is central to *person-centred* care may also neutralize the power hierarchy between "patients" and their health care providers, as it sets the foundation for them to be partners in care and bypasses the traditionally assigned patient role and its associated power inequities (as discussed previously in relation to *patient-centred* care).

More recent definitions suggest that *person-centred* care should also be considerate of the environment or context in which care is delivered (e.g., systems issues, policy impacts, access to care), should consider the person's capacity to engage in self-care (e.g., influence of the social determinants of health) and acknowledge that reporting on the patient experience, from the individuals' perspective, is an integral aspect of *person-centred* care (Bidy et al., 2015; CPAC, n.d. a, b, c; Fitch et al., 2008; Kitson et al., 2013). I anticipate that inclusion of a focus on the survivor's care environment, as well as the structures and contexts that might shape their capacity for self-care, adds an element of equity-oriented care that is not obvious in older *patient-centred* definitions. Also, I anticipate that adding an evaluation of the survivor's experiences increases the

likelihood that survivors will receive high quality care, as long as the data also is used to refine models of care and resources to better align with survivors' needs and desired outcomes.

Based on this review of definitional differences between *patient-* versus *person-*centred care, I believe that the key elements underpinning a *person-*centred perspective are more likely to maximize opportunities for survivors to receive equitably high quality care. Returning to the survivorship documentary sources reviewed in this study (which often used *patient* and *person-*centred care language interchangeably), I examine these documentary sources in terms of how they support the key elements underpinning *person-*centred care. These key elements are synthesized into three broad groupings including: a) maintain a holistic focus, b) consider context and structures, and c) engage the survivor as partner in care (i.e. person first, values based care, relational care, evaluation of survivor experience and outcomes). Through this critical examination, I gained insight into some of the gaps and inconsistencies regarding how *person-*centred care has been taken up into the survivorship vernacular. I also gain perspective on how the documentary sources' positioning (and/or absence) of *person-*centred care may support, enhance and/or detract from equity and high quality survivorship care in Canada.

4.4.2.2.1 Maintain a holistic⁵⁵ focus. Despite using the language of *person-*centred care and purporting to support survivors to transition to their “new normal” and return to health after primary treatment ends, I was surprised to find that most of the documents reviewed continued to prioritize and mainly focus on survivors' disease and treatment-related factors. For example, in reviewing survivorship care plans (see for example ASCO, n.d.), I noted a significant weighting on treatment summaries, anticipated physiological late and long-term effects and disease surveillance recommendations. This is in contrast to the minimal inclusion and positioning of

⁵⁵ A holistic view includes physical, psychological, emotional, social, spiritual, informational, and practical needs of survivors in a way that is inclusive of their beliefs, values and goals for health and well-being (Fitch et al., 2008; CPAC n.d. a,b,c)

survivors' holistic needs (e.g., psychological, emotional, social, spiritual, informational, and practical) within survivorship care plans, giving me the impression that managing survivors' disease-related care needs are given prominence and being prioritized over addressing all other holistic needs. The disease-focused organizing structure of most survivorship clinical guidelines (see for example, Cohen et al., 2016; Resnick et al., 2015) was another key example of where I observed a disconnect between the stated intention of person-centred care, without the necessary holistic components to ensure a person-centred approach to care.

I find this disconnect between the intention of person-centred care, and the privileging of disease-related needs/obscuring of holistic needs quite concerning. This disconnect has the potential to limit high quality care and may further marginalize individuals for whom the social determinants of health are challenged.

4.4.2.2 Consider context and structures. Layering onto the minimal focus on holistic needs, another intriguing tendency I noticed was that very few documents specifically included a focus on understanding survivors' environments, contexts and the structures influencing their ability to achieve high quality survivorship care. The majority of the documents maintained a focus on survivors' individual behaviours (e.g. self-care, healthy lifestyle choices, cancer screening behaviours), and in some cases what health care providers and the system should offer to optimize survivors' care. I believe this lack of consideration of the contexts and structures (e.g. oppressive policies, racialized environments, lack of consideration of the social determinants of health (SDH)] within survivorship documents and vernacular are a significant weak point and issue limiting equitably high quality survivorship care for all. Without consideration of these contexts and structures, interventions to promote survivorship care will only be aimed at individual survivors, without considering the barriers and facilitators that impact their agency/capacity to promote their health. As a result, survivorship care programs, models of care

and resources will continue to be designed for those whom hold societal positions of privilege (e.g. white, upper middle class, and educated individuals and those with common cancer types such as breast cancer), and without consistent consideration of those for whom the SDH are marginalized.

This privileging of certain groups of survivors is likely already taking place, as observed across documentary sources, in the placement and accessibility of programs designed to maximize survivors' self-care capacity. For example, self-care capacity building, health promotion and wellness programs and resources are most often located in the private or not-for-profit sector (e.g. Callanish, Wellspring), in urban settings, using an out-of-pocket fee structure. Only a few programs are located in the publicly and/or research-funded sector (e.g. Electronic Living Laboratory in Cancer Survivorship Research (ELLICSR)], and in web-based formats (see for example Maheu & Parkinson n.d.). While on the surface it seems reasonable that these programs are placed in a variety of settings to improve accessibility for a diverse range of individuals, upon a closer look I can see that the structures influencing the positioning of these programs (such as SES, rare cancer types, language and cultural preferences) may not have been overtly considered and may in fact be one more barrier to *person*-centred care for some survivors. Also, this positioning of programs gave me the impression that support for survivor self-management and capacity building for health promotion and wellness is not a priority within the publicly funded health care system, despite being touted as a key element of person-centred care.

4.4.2.2.3 Engage survivor as partner in care. Another interesting trend that I noted was that most of the documents used the language of "patient" versus "person", and positioned the survivor as the recipient of, rather than partner in care. This trend was particularly strong across documents and reports situated within conventional, biomedical settings or those used primarily by conventional health care providers. For example, clinical practice guidelines, while intended to

guide clinician practice to promote *person-centred* survivorship care, also use language that empowers the clinician to transfer knowledge to the survivor (without reciprocity). My impression of the vernacular within these documents was that they were positioned to ensure that a checklist of activities are performed, with disease monitoring activities taking priority, rather than an emphasis on understanding what is most important to the individual, including their beliefs, values and goals, and providing survivorship care according to matters most to the individual.

Reading through the guidelines and other documentary sources, I also was left with the impression that clinicians hold greater power within the patient-clinician relationship, with survivorship care being constructed to ensure clinicians' professional responsibilities are clear and executed, and the survivor knows when and how to engage with the system and health care providers to monitor their disease and manage late effects. I did not commonly encounter language that encouraged survivorship models of care to foster knowing the person first, understand their beliefs, values and goals, nor to engage in a reciprocal partnership with survivors to design and deliver care that matters most to them. Further, another intriguing tendency I noticed was that there was very little representation of the actual voices or perspectives of survivors, even though this is often positioned as a central tenet of person centred care.

There were two surprising and notable exceptions, however, that I observed among documentary sources at community and national levels that *did* focus on engaging survivors as partners in care and are worth mentioning here. At the national level, the Canadian Partnership Against Cancer (CPAC) Person-Centred Care Portfolio (CPAC, n.d.a), specifically aims to “rebalance the focus”⁵⁶ of cancer care back onto patients and families, and to ensure that the

⁵⁶ The “Re-balance Focus” portfolio within CPAC’s organizational structure and strategic plan, initially established in 2006, has evolved over time into the *Patient Journey* portfolio (to include a focus across the

cancer care system is responsive to their holistic as well as disease-related needs. I found the language within this CPAC portfolio to be very specific and directive regarding increasing the emphasis on including survivors' voices and perspectives across all of CPAC's strategic plan documents, including placing survivors as key committee and working group members on most initiatives. I found this disconnect between the very directive person-focused language at the national cancer control level, and the actual uptake of including survivors' voices, perspectives, and needs as a central tenet across most of the other survivorship documentary sources perplexing. I was left wondering what factors, contexts and structures (beyond the definitional slipperiness discussed here) may be at play to prevent uptake of person-centred care across other documentary sources, despite a clear national standard and directive. Potential influencing factors are explored further in Phases 2 and 3 of this study.

The other notable exception to the exclusion of person-centred language within documentary sources was across most of the community based survivorship wellness programs and resources (see for example Ottawa Integrative Cancer Centre, n.d.; Young Adult Cancer Canada, n.d.). Compared to the survivorship documents based/located within the cancer treatment setting, I found that community-based survivorship programs and resources tended to use language focused on knowing the person first, understanding their beliefs, values and goals, and including survivors' voices within the design and delivery of programs. I found this discrepancy between the inclusion of the survivor's voices within community-based programs, and the exclusion of those same voices within the conventional setting, while both claiming to provide person-centred survivorship care, to be very interesting. I believe a more in-depth examination of why this discrepancy exists, including the factors and structures shaping this discrepancy are important to

cancer trajectory, rather than mainly on treatment), and more currently in 2017, it evolved into the *Person-Centred Perspective* portfolio (to clearly articulate and embed the value of person-centred care across all other portfolios and across the complete cancer trajectory).

understand. Corrective actions can then be taken to modify these factors and structures, to ensure survivors' voices are included in all programs and resources; without this voice, it is difficult to truly engage survivors as partners in care, and to enable person-centred care for all.

One final point related to engaging survivors as partners in care that I believe is important to discuss in more detail was the variable interpretation and integration of evaluation measures that include the survivors' voice and experiences. Similar to the definitional fluidity of "survivorship" and "person-centred care", I observed the terminology regarding "patient-reported outcomes/patient reported experiences" to be somewhat fluid, depending on the source of the document. For example, a number of documents originating from the biomedical, treatment focused system conflated biomedical-dominant measures, such as symptom distress scores, as the standardized key measure of patient experience; while documents originating from supportive care and wellness programs used language that was inclusive of a wide range of survivor perspectives, experiences and outcomes. These different interpretations of patient reported experience and outcomes left me wondering why there is such wide variation, and what are the implications of this variation for achieving person centred care. I believe it is essential to capture survivors' experiences and outcomes that are meaningful to them (as per person-centred care definitions and philosophy), so that programs and resources can be evolved to more adequately address these needs. As with other discrepancies and disjunctures noted regarding person centred care throughout this chapter, I will explore what is shaping these differences in phases 2 and 3 of this study, and discuss how they may be modified to promote high quality person centred survivorship care for all.

4.4.3 Population- and system- focus dominance. A third broad-reaching issue that I noted across the documents I studied was the dominance of *population-* and *system-*focused care structures and resources, which I believe has the potential to create tensions, blind spots and

challenges to achieving equity and high quality *person-centred* care. I observed this population- and system- focused dominance consistently across the documentary sources reviewed – among the clinical tools and resources used to guide survivorship care, in the structure of survivorship models of care that include strategies to improve access to care, in strategies to move survivors efficiently through the care system, in the structure and uptake of evaluation metrics, and in the funding streams that support survivorship care programs and resources. Each of these areas is discussed below in more detail.

4.4.3.1 Practice tools and resources. Survivorship clinical guidelines and care plans were discussed across most documents reviewed as key clinical resources to guide the care of cancer survivors. However, these key resources draw upon evidence-based medicine principles, and are therefore designed to respond to population norms, or the “average” cancer survivor, which may not align well with guiding individualized, person-centred care. These clinical tools, for example, emphasize and foreground aspects of care that that may require less individualization, such as those focused on the disease (e.g. recommendations for disease monitoring and recurrence surveillance), with little emphasis on aspects of care that may require more individualization, such as holistic needs (e.g., psychosocial, emotional, practical, spiritual). With evidence-based medicine as a key concept and driver in modern cancer care, including survivorship care, I would expect to see a greater emphasis within clinical guidelines on aspects of care at a population level. However, I anticipate that this (unopposed) dominance of population-based clinical tools and resources (that may only provide direction to general aspects of care) will create a significant tension in moving toward the equally important goal of delivering person-centred, individualized care. I am concerned that this disjuncture between a heavy dependence on population-based clinical tools, without consideration of additional structures that ensure person-centred, individualized care is achieved, will continue to negatively impact high quality survivorship care.

4.4.3.2 Survivorship model of care structures and processes. Across documents discussing optimal survivorship model of care structures, I observed a similar system-focused dominance and resulting tensions that may impede achieving person-centred care. Most of the discussions within documents concentrated on access to care and care coordination at the system level, describing and explaining the gaps in the system of care and how survivors may be supported to move across those gaps within the system. In these discussions, access to care was equated with person-centred care, and strategies to improve access to care were the key focus. The introduction of navigator roles is an example of a strategy discussed across documents to improve access to care by helping the survivor bridge the gaps across siloed systems of care (e.g. between end of primary treatment within the specialized cancer setting and return to primary care). While on the surface this seems to be a reasonable approach to improving access to care for survivors within a complicated health care system, I was concerned about the lack of dialogue regarding the need to refine or build systems around survivors' needs so that external navigators are not needed. Although challenges within the survivorship system were noted in many documents, strategies to address the core system challenges were not the focus; rather the focus was on adding additional strategies or "work arounds" to compensate for the fragmented and complex system. I became curious as to why the priority improvement strategies included maneuvering the survivor to fit the system, rather than massaging the system to fit the survivor. This raised questions for me regarding what factors are at play that seemingly give "the system" more power than the survivor, despite the envisioned and stated goals of person-centred (versus system-centred) care.

Layered on top of the compensatory "work around" strategies such as navigator roles, I also noted frequent language across the documentary sources about valuing efficient movement of survivors through the system. In some reports, efficient movement through the survivorship care system was equated with high quality, person-centred care. However, most of these discussions

focused on the population level, where attention was maintained on the “average” survivor, focusing on their disease-related needs, without consideration of the unique, holistic needs of individuals.

Another concern that I have regarding the emphasis on efficiently moving survivors through the system, combined with a general, population-focus and disease-related need prioritization, is the impact on vulnerable populations who do not fit this normative mold. The population or standardized “norms” for survivorship care may not be appropriate or helpful for vulnerable populations to have their needs met, and may inadvertently leave out or further marginalize some groups. For example, comparing Indigenous survivor populations to standardized “norms” (which are largely developed from Caucasian upper middle class urban-dwelling individuals) may move Indigenous survivors further away from person-centred high quality care by adding layers of unintended colonization, racialization and culturally unsafe approaches. Instead of comparing groups, a more culturally sensitive approach to care includes moving forward in their unique journey, rather than comparing to a standardized norm that does not reflect their cultural or other norms and aspirations (Browne et al., 2009; Gerlach, 2012; Gordon & Chen, 2017). Looking forward, I believe it will be important to establish and use a broader range of approaches, beyond the singular use of population-based norms, to support groups and individuals toward equitable, person-centred, high quality survivorship care.

The organizing structure of many survivorship models of care around tumour groups/types of cancer also raised questions in my mind about the capacity, within this current orientation, to achieve equitably high quality person-centred care. For example, as I critically reviewed survivorship documentary sources, I noted that those cancer types with associated evidence-informed survivorship guidelines available (e.g. breast, prostate, colorectal) were more likely to have formal survivorship programs, and these programs were almost exclusively based within, or

in association with, a cancer treatment setting. Those cancer types without cancer type-specific survivorship guidelines generally did not have a specific survivorship program. Although there are key elements of survivorship care that are specific to survivors' cancer type, there are also significant common unmet needs across survivors that have little to do with their type of cancer (e.g. fear of recurrence, fatigue, cognitive changes, sexual health issues, return to work issues) (Brennan, Butow, Spillane, & Boyle, 2016; Burki, 2015). Survivorship programs organized around these common (holistic) unmet needs have the potential to reach larger numbers of survivors, increasing access and removing structural barriers to survivorship care. Further, I was perplexed to find that although there exists a sentinel high quality Canadian clinical guideline to direct the organization and care delivery structure of survivorship services and psychosocial-supportive care best practices of survivors (Howell et al., 2011), I could not identify a survivorship program that used this guideline to inform its structure or programming. Based on my review of documentary sources, it seems that survivorship clinical guidelines that are organized around cancer types have been more readily taken up into practice, even though this may serve a small subsection of survivors and may not address their holistic needs. This disjuncture left me wondering what the factors at play are, that may influence the privileging of cancer type/biomedical-driven survivorship models of care and resources, and what barriers are preventing a more holistic, person-centred approach and structure to survivorship models of care (MoC).

Critical reflection on the location and scope of survivorship programs and services (e.g. treatment settings, community based) led to another interesting observation across the documentary sources. These critical observations illuminated some of the potential structural and systemic factors influencing how these programs have been situated, and as a result, their capacity to support equitable, coordinated and high quality survivorship care within the cancer

care/health care system. Most survivorship MoCs and programs in the treatment setting focus on the transition from the end of treatment to primary care, with very few considering survivor needs beyond the physical (e.g. fear of recurrence, fatigue management, emotional support, return to work, sexual health) after this transition. Given the emphasis on the biomedical model and EBM in the treatment setting, I was not surprised to observe that survivorship MoCs and programs situated in the treatment setting generally focused on disease monitoring and recurrence surveillance and were organized according to specific cancer types. Conversely, survivorship MoC and programs situated in the community setting were more likely to specifically address holistic needs (e.g. health promotion, lifestyle, wellness) and generally were not organized in relation to a cancer type. With a few exceptions (see for example, ELLICSR), these community-based programs and resources did not offer a full range of services to meet a broad range of holistic needs. Given the goal of coordinated, holistic person-centred survivorship care, I am curious to understand whose needs this best serves using a siloed approach (i.e. disease focus in treatment setting; holistic focus in community setting) to survivorship care? Is this setting-specific arrangement driven by and organized to optimally to meet the broad range of survivors' needs? Or is this arrangement driven by other factors such as funding structures, policies, and other historical and contextual factors?

Exploring the survivorship documentary sources from an equity perspective as it relates to location of survivorship programs within cancer and primary care systems also provided some interesting insights. Although there is a paucity of documents that discuss or include equity elements in the cancer care system, there exists one sentinel national CPAC document, published almost a decade ago, included a discussion paper, proceedings from a national stakeholder workshop and recommendations to address inequities broadly in cancer care (Palaty, 2008). The issues highlighted and recommendations made to address inequities (e.g. integrating diversity and

equity issues across all aspects of cancer care; addressing cultural safety; working across social, health and other silos) also are relevant to the survivorship population. However, I found it difficult to ascertain to what extent, if any, these recommendations have been further developed and/or taken up into cancer care broadly, or specifically into survivorship care. This gap between recommendations and action left me with the impression that inequities in cancer care may not be a priority, and also made me question what the barriers are to moving these equity-informed recommendations forward.

A review of equity-informed documents within the primary and community care setting revealed a different story. I did find a focus on equity across documents reviewed specifically related to primary and community care (i.e. not cancer or survivorship specific), as well as those focusing on enhancing person-centred care within British Columbia (see for example, British Columbia Ministry of Health, 2015b). I included these documents in this study to explore opportunities for positioning aspects of high quality cancer survivorship care outside of the specialty cancer treatment setting in this Province. Compared to cancer and survivorship care-focused documents, these primary and community care focused documents were much more explicit in identifying equity as a key component of care; however, most of the discussion concentrated on equity from a population focus. The same documents also included person-centred, individualized care as an essential element of high quality care yet did not offer insights or strategies to negotiate the tensions of ensuring equity among groups while still achieving person-centred, individualized care for all.

I found it interesting to consider and reflect on why there is such a gap between equity elements included in primary/community care documents, and the lack of this focus within cancer survivorship documents. While I doubt that surviving cancer negates a need to focus on equity and the SDH, I am intrigued to better understand what factors layer and intersect to

obscure this focus within cancer survivorship care. These factors may range from slippery definitions of survivorship and person-centred care, to dominance of the biomedical model and EBM, to how we evaluate and fund survivorship care. These and other factors will be explored in more detail in phases 2 and 3 of this study.

One final point worth examining here is the focus across documentary sources regarding where survivorship MoCs and programs *should* be placed across the cancer control continuum. The focus within key survivorship reports is largely at the level of physicians (i.e. oncologists and primary care physicians (PCP)), with survivor voices almost completely absent. Further, oncology nurses' voices are rarely observed in this discussion, except in regard to nurse-led survivorship clinics. Among the dominant physician dialogue, I observed a potential power hierarchy that placed oncologists in a greater position of power, largely drawing this source of power from their specialized oncology knowledge and experiences. These oncologist voices commonly indicated that the treatment setting was the optimal environment for “survivorship care” (mostly referring to disease monitoring and recurrence surveillance). However, I also noted an increasingly strong voice from primary care physicians, who have developed greater oncology knowledge and expertise, to advocate for aspects of survivorship care that may be moved to the primary care setting, where a broader range of survivor needs may be addressed long-term. I am curious to understand how this power hierarchy will influence how survivorship care models and resources unfold going forward, and how a renewed national emphasis on person-centred cancer care (see for example, CPAC, Person Centred Perspective portfolio (CPAC, n.d.b), among other factors, may disrupt this power hierarchy that seemingly marginalizes survivors' voices.

4.4.3.3 Evaluation metrics. Exploring the documentary sources with regard to how survivorship MoCs and resources are typically evaluated provided me with a new lens with which to view some of the values held by the cancer system with respect to survivorship care. Despite

identifying person-centred care as a key element of high quality survivorship care, the majority of the evaluation metrics utilized were aligned more closely with population and system (including measures of efficiency) outcomes. For example, in survivorship guidelines and care plans, standardized population-based norms were used to describe desired survivor behaviours (e.g. related to screening, lifestyle and other health-promoting behavioural changes). As is typical for guidelines, no mention was made within these documents about how to contextualize these behavioural norms for unique individuals or populations (e.g. young adult, older adult, those with additional chronic health conditions, Indigenous populations). Further, these guidelines generally do not provide direction to consider the contexts and structures (e.g. poverty, racialization) that may shape survivors' capacity to engage in and maintain these normative health promoting behaviours.

However, I did note a beginning shift in provincial and national survivorship initiatives to include person-centred metrics (e.g. patient reported outcomes (PROs) and patient reported experience measures (PREMs)). I found it perplexing, however, to see how many of these person-centred metrics were somewhat contorted when taken up into practice. Instead of capturing the survivor's experience and meaningful outcomes without mediating interpretation by clinicians (Gordon & Chen, 2017), many of the survivorship programs put system-imposed limits on the expression of this survivor experience. For example, one program described pre-selecting key elements and/or items within measures of PRO/PROMs to be included in their program outcomes, limiting the possibilities for survivors to have the full range of options within which to report their experiences and values. Other programs used a sub-set of symptom distress scores that were meaningful to the program, equating this as a "person-centred" metric.

These observations caused me to pause and consider, why are these population and system metrics continuing to take priority despite a shift to include person-centred perspectives as a

priority? What are the factors that may be quietly operating that keep the evaluation at the population and system level? Whose needs are served by this? What must shift to make evaluation of person-centred perspectives a reality in “standard” evaluation metrics? These questions and points of disjuncture will be considered as I move through phases 2 and 3 of this study.

4.4.3.4 Funding structures. Examining the sources and patterns of funding allocation for survivorship programs, resources and health professionals also may assist in revealing the values underpinning survivorship care, as well as some of the challenges to embedding survivorship care into an already underfunded cancer care system in Canada. Across the documentary sources reviewed, I noted that funding for survivorship programs and resources comes from three main sources including: a) core operational funding, if the program was situated in a cancer treatment setting, b) pilot and research grants, and c) advocacy groups and other public not for profit donations.

I found it interesting (but not surprising) that despite being considered a key phase in the cancer control continuum, stable funding for survivorship programs and resources is variable, and is not universally considered a part of core funding even when delivered within a cancer treatment setting. I found many examples where a survivorship program was started with pilot funding and research grants, and only through the fortitude and leadership of the research team was stable funding for a larger, established program (usually a mixture of research, advocacy group, foundation and other “soft funds”) secured. While very creative, I see that this piecemeal funding approach has led to a country of survivorship “pilot-itis” where some excellent programs have been established but cannot be scaled up to serve the needs of all survivors. I do, however, see the challenges to not taking a piecemeal approach to funding in a fiscally restrained cancer care environment; if one cannot establish a pilot program that demonstrates improved survivor

outcomes, there is no hope of ever gaining traction or uptake into any core operational budget which may ensure longevity and integration of the survivorship program.

Also related are the minimal research dollars allocated, and the focus of calls for research proposals for survivorship care in Canada. In reviewing cancer research funding reports, I noted that funding available for cancer survivorship research is disproportionately low relative to that focussed on care for individuals along other points of the cancer control spectrum, such as during cancer treatment (Canadian Cancer Research Alliance & Canadian Health Research Collection, 2013). Research grants inclusive of cancer survivorship remain heavily weighted for disease-focused activities, such as physiologic late effects of cancer treatment. However, over the past decade, there has been increased funding for survivorship care delivery and quality of life research investments. Many research grant competitions continue to be organized around types of cancer, with breast, prostate and colorectal being the most frequently focus of grant funding competitions.

Primary care physician fee reimbursement schedules also may be an important funding-related factor shaping the scope of survivorship care services in primary care settings. For example, I noted that these reimbursement schedules have a dominant focus on disease-related, incidental care and place minimal value on addressing long term, individual chronic and complex needs. A disconnect between many survivors' needs post primary treatment (i.e. ongoing, complex, psychosocial and emotional elements) and the structure of these reimbursement schedules may be a limiting factor to optimally meeting survivors' needs in the primary care setting.

The tensions and disjunctures created by the layering and intersection of a variety of issues that influence funding for survivorship care creates a complex environment within which to establish high quality survivorship programs and resources with longevity. Exploration of these issues (e.g. nascent stage of survivorship program development with early evidence to guide

practice; lack of consensus about where survivorship care is best delivered; fiscally restrained cancer care environment; cancer treatment settings tied to biomedical and EBM approaches; minimal allocation of survivorship research dollars; physician reimbursement schedules that under resource key survivorship care needs) may necessitate a different approach to survivorship program funding, and will be further investigated in phases 2 and 3 of this study.

4.5 Phase 1 Summary and Key Insights

In the first phase of this study that included a critical textual analysis of survivorship documentary sources, I gained new perspectives on how the survivorship challenge has been taken up within cancer care in Canada. In particular, I developed new insights regarding some of the key challenges, gaps and inconsistencies that may be impeding progress toward equity and high quality in cancer survivorship care.

Some of these key insights included definitional fluidity of *survivorship* terminology. Depending on the use of broad, mid-range or narrow definitions of cancer survivorship, variable impacts may be experienced in terms of survivorship resource and model of care development, scope, comprehensiveness, access and equity. An interesting “curative versus non-curative” binary also added complexity, potentially privileging survivors receiving curative treatment, across all survivor definitions. An added layer of complexity included the positioning of palliative care concepts in relation to survivorship, further blurring the lines and dimensions of survivorship, curative versus non-curative “silos”, and palliative care.

Definitional fluidity and conceptual slipperiness was also very apparent in *patient-* versus *person-*centred care definitions and language. Returning to the literature to find a common perspective on the definitional differences between patient- and person-centred care, I offered a rationale for why a *person-*centred care approach is optimal for achieving equitably high quality survivorship care. Key elements of person-centred care include the need to: a) maintain a holistic

focus, b) consider context and structures and c) engage the survivors as partner in care (i.e. know the person first, values-based care, relational care, evaluate survivor experiences and outcomes). A critical review of the documentary resources with respect to these key elements, suggested that overall, person-centred survivorship care is not likely to be optimally enacted in Canada. A variety of factors could be at play, including biomedical model and EBM dominance, a lack of focus on the SDH and their influence on individual circumstances and behaviours, a lack of consideration of factors that influence access to care, power hierarchies that prevent survivors from having a central voice and being true partners in care, and evaluation metrics that benefit the system but do not communicate survivors' experiences or meaningful outcomes.

Another key insight that I gained from this phase 1 analysis is that there is dominance of *population-* and *system-* focused structures that have the potential to create tensions and challenges for achieving high quality person- centred survivorship care. An example of these structures includes practice tools and resources that draw upon EBM principles to provide direction for care of populations, but cannot direct individualized, person-centred care. Survivorship MoCs that focus on access to care without considering the factors shaping this access are another example of a system- dominant structure that may oppress individuals, particularly vulnerable groups. Efficiency drivers, MoCs organized around cancer types, a siloed approach to survivorship programs that offer a separation of disease-focused versus holistic-focused survivor needs, and power hierarchies that marginalize survivors' voices are other examples of structures that dominate at the system and population level and may prevent forward movement toward high quality person-centred care.

Evaluation metrics and funding structures also were examined with respect to how they contribute to high quality survivorship care. Tensions were exposed within survivorship evaluation metrics, highlighting a gap between the goal of measuring person-centred care, and

yet most metrics are in reality tied to system efficiencies and population goals. Other metrics may further marginalize vulnerable groups, by (inappropriately) comparing them to standardized norms. Examination of funding structures also revealed tensions that may create an unstable foundation upon which to fund and embed high quality survivorship programs long term. Some funding-related tensions include the nascent stage of survivorship program development, a lack of consensus about where survivorship care is best delivered, a fiscally restrained cancer care environment, dominant biomedical and EBM approaches, minimal allocation of survivorship research dollars and physician reimbursement schedules that under- resource key survivorship care needs.

The final key insight gained through this critical textual analysis pertains to the almost complete invisibility of equity language and concepts across all survivorship documentary sources. Although a very limited equity focus was present at the population level (i.e. comparing groups to find differences that may be morally concerning), there was negligible consideration of the influence of the SDH on shaping survivors' individual capacity for self-care and experience of survivorship, potentially contributing to serious systemic inequities as survivorship care evolves into the future.

These phase 1 insights and perspectives will be used to inform phases 2 and 3 of this study, to provide direction in exploring key concepts, themes and complexities in the interviewing of survivors and key stakeholders. I will also further explore these phase 1 insights and perspectives in the analyses conducted for phases 2 and 3.

CHAPTER FIVE: Findings from the Secondary Analysis

5.5 Introduction to the Secondary Analysis

Phase 2 of this study included a secondary analysis of a subset of the Communication in Cancer Care (CCC) database (Thorne et al., 2014). This secondary analysis of the CCC database subset offers insights into individuals' experiences of the transition from end of primary cancer treatment to survivorship care, and it provided some direction for key areas to explore within Phase 3 of this study (interviews with survivors and stakeholders). For individuals completing primary treatment, this part of the cancer journey has been identified in the literature as fraught with challenges and unmet needs from survivors' perspectives (Hewitt, Greenfield, & Stovall, 2006). Understanding the perspectives of individuals as they move through the end of primary treatment may offer insights into how to best support this transition, and how the system can be better designed and health care providers better prepared to meet survivors' needs.

As described in Chapter 3, the Communication in Cancer Care (CCC) qualitative database houses interview transcripts of 125 adult cancer patients offering over 500 interviews over a 7-year period (2005-2012), focused on understanding cancer patients' changing communication needs and preferences across the cancer trajectory (Thorne et al., 2014). Thorne and Stajduhar (2012) previously analyzed a subset of these interview participants (N= 14), focusing specifically on the transition from the end of primary cancer treatment to survivorship care, to explore cancer patient perspectives and needs regarding communication in the transition to survivorship care, with the aim to better inform survivorship supportive care services and systems. Since the publication of this analysis in 2012, five additional "end of primary treatment phase" participants were added, bringing the total to 19 participants for my secondary analysis of a subset of the CCC database for this current study.

This subset of the larger database for this study included an average of 3.2 individual interviews (range=1-7) for each of the 19 participants, with 61 transcripts in total analyzed. The participant subset consisted of 15 women and four men ranging in age from 23 to 69 (mean=52.2 years). The participants reported a range of primary cancer sites including six breast, three hematological, one gynecological, two prostate, four gastrointestinal, one lung, one osteosarcoma, and one melanoma. The participants included those diagnosed with early and advanced stages of cancer, some living with metastatic disease, and some who self-identified as cured or in remission. The participants self-identified as Caucasian (n=15) or of Asian descent (n=4). All but one participant lived near a major urban cancer treatment centre in either the Lower Mainland or the Vancouver Island area; this one participant lived in a rural location in northern British Columbia.

Using a constant comparative approach, I analyzed the series of transcripts for each participant, in addition to comparing each set/series of participant transcripts in the context of all other participants. Through this iterative cross-comparison approach within and across sets of participant transcripts, I inductively developed a thematic summary of participants' experiences of and access to survivorship care. Throughout this analysis, I also considered what are the various social, economic, political, and personal factors that may be influencing their access to and experiences of survivorship care. Finally, where available, I explored their envisioned system and recommendations for high quality survivorship care.

5.2 Findings

Across all of the transcripts included in this secondary analysis, participants recounted issues and experiences that got in the way of feeling that they had received high quality survivorship care. These issues and experiences ranged across the cancer care system, from the early diagnostic period to the survivorship phase post treatment. While most participants felt that their

basic cancer-related biological needs to stop or slow the progression of their cancer were met, they also felt that their unique and holistic needs were not considered a priority within the cancer treatment and care system. Analysis of these issues and experiences described by survivors revealed a number of elements underpinning our cancer care system that are consistent with this idea that what patients consider high priority needs and goals, especially those in the psychosocial domain, were not a priority within their cancer care plan.

Keeping the definitional challenges raised in the phase 1 findings (Chapter 4) in mind, in these phase 2 findings I used a standard language convention to define survivor and survivorship. The term “survivor” in this chapter refers to cancer patients who have completed primary treatment, and “survivorship” refers to the phase in the cancer journey at the end of primary treatment. Adhering to these standard definitions aligns with the definitions used in the Communication in Cancer Care data base (Thorne et al., 2014), and helps prevent slippage between the terms in this secondary data analysis.

5.3 Transitioning to a New Normal

To set the stage for an understanding of the observations and reflections about survivorship system gaps and potential inequities, it seems important to begin with a brief description of what patients thought they ought to be experiencing in the transition beyond active cancer treatment and toward whatever comes next, and why it did not seem to work out that way.

5.3.1 Life after cancer treatment. Almost all participants described ambiguous feelings of being grateful yet unprepared to finish primary treatment and return to their old, yet changed, new life. Many participants described being in treatment as creating a reassuring sense of being in control over their situation, where chemotherapy and radiation were actively killing their cancer cells. As one explained, “I felt like the chemo was keeping me healthy...that sounds really weird... its killing all the bad cells. So when you’re done chemo, you feel so out of control,

totally vulnerable... I was so down and depressed.” Further, many described feeling as though they had been “dropped” or abandoned from the cancer care system and specialized oncology health professionals once their active treatment phase concluded, with minimal or no preparation to manage the transition. Some participants described this period toward the end of primary treatment as being associated with more stress, poorer sleep, more side effects to manage, fear of recurrence and greater anxiety about how they will manage post treatment. Discussions with oncology health professionals (e.g. oncologist, Registered Nurse) about self-management strategies regarding ongoing cancer-related needs into the survivorship period post treatment were infrequent. A 44-year old woman with gastrointestinal cancer commented,

It's on the record that this [preparation to manage the transition post primary treatment] is really important. This is not a frill. You know, to sort of be left, ... ok physical treatment is crucial...but then to kind of drop off the end ...and have no formal transition point...is really harmful. For me it was very difficult...and I got very depressed.

In retrospect, one woman treated for breast cancer summarized the transition:

It is really abrupt... all of a sudden you're dropped... it's good because, in one way, going to appointments when you're in treatment is a full time job in itself but then it's kind of like you feel all alone all of a sudden like no one is checking in on you. There is a period of probably about a year after I got finished treatment where I felt really paranoid the cancer is going to come back but no one is watching me.

In this context, many felt that having some kind of strategy in place near the end of primary treatment would aid survivors in managing the ongoing physical, psychological, emotional, financial, practical, and informational challenges post treatment.

In addition to feeling unprepared to leave the cancer expertise and support within the cancer treatment system, most participants wrestled with feeling vulnerable that their cancer may recur,

and that they had little guidance on what to expect to identify and manage any potential recurrence. Many participants described negative, long-lasting psychosocial and practical implications as a result of the lack of preparation to manage the transition post treatment. One young woman three years post treatment completion for breast cancer remarked,

It's like everyone's talking about getting back to normal and you can't really get back to normal. I mean, your energy is not the same and you've changed, but you don't have a support... I'm still struggling with that and I have friends who've been in remission 10 years who are still struggling with that. It's just really hard to know how to get back into life. I mean, before I had my diagnosis I was in so much stuff and now I'm doing probably two percent of what I used to do.

Some participants talked about the changes in relationships with others during this transition. For some, their external appearance did not align with their internal changes, where they were still psychologically and emotionally impacted by the cancer experience. They looked the same but felt they had changed inside. An older woman-post breast cancer treatment reflected,

I'd run into someone and then the initial reaction is, oh you're looking good and oh, glad you're back to normal...You get that comment over and over and then sometimes you just smile inside and sometimes you make a comment about it. I said, "Well I may look the same." How many times I've said that? I look the same on the outside but the inside has changed and you know, it has. I'm not the same, same person going back.

Another lingering concern associated with the post-treatment transition was financial. Although Canada's publicly funded health care system covers many drug costs, the associated supportive medications, travel to locations with specialized services, accommodations, and lost income are not commonly covered. Many participants began to confront the impact these added costs would have on their families going forward, whether or not they survived the cancer. One

older man with lymphoma described being worried about the financial impact of a recurrence on his family:

I've never really felt that I was a financial burden on the system. I've worried that I was a financial burden on my wife. If we end up with some greater expenses again [due to recurrence] then, you know, she's got another thirty years. I'm always cognizant of insuring her financial stability. There's not a lot we can do about it...that's just the way things are.

Despite having assumed that they would return to their old life post treatment, most participants described a process of coming to understand and manage their “new normal” post treatment. Slowly, over time, many participants began to integrate new strategies post-treatment completion to manage their bio-psycho-social unmet needs, despite lack of societal or system support for integrating this new normal.

5.3.2 Societal expectations. For many of the study participants, there was a mismatch between their own experience of life after treatment completion, and what they perceived as societal expectations of how a survivor ought to feel and behave. This could create additional layers of distress and suffering to complicate their integration process. For example, a 64-year old woman who had completed breast cancer treatment participated in a breast cancer fundraising run. She described her experience of reluctantly being required to wear a pink bracelet meant to symbolize the triumphant nature of beating cancer and somehow being transformed by the experience. She felt conflicted by her own “less than triumphant” post-cancer treatment feelings that did not match the symbolism in the pink bracelet. The bracelet became yet another reminder of how she did not fit in and how she had not lived up to expectations. She says,

I bought the pink bracelet and took it off this morning because I put it on thinking I should have it because I have this cancer...[But] while I wore it I felt manacled, chained to the

label... I'm going to get rid of this bracelet when I get home, it just bothers me ... so I'm throwing it away... I just sort of feel free. Yeah, very good to take it off, I'm done, period.

Another young woman post-breast cancer treatment talked about the perceived stigma attached to “giving in” to the fatigue and other ongoing post treatment symptoms that interfered with her return to work. From her perspective, she felt a societal expectation that once her treatment was completed, she was expected to return back to “normal” and return to work:

I tried to work during the radiation and immediately after treatment ended...It's a stigma for young people who are trying to get ahead in their career not to work during or after cancer treatment. It was killing me and I had two little kids. But I did it anyways because that's what was expected of a young career woman with cancer.

She also felt it was considered inappropriate to speak of these lingering depression and mental health challenges. “They're supposed to be thankful and grateful for your life because, you know, you're still alive. So I don't know if it's like a taboo to say, you know I'm still depressed. I mean, it sucks and you know, like you're wallowing or whatever.” This mismatch between survivors' actual lived experience compared to the cues they picked up around them with respect to what they were supposed to be experiencing made it difficult to manage relationships, small children and careers. If they were unable to sustain an impression of being joyful and grateful to have lived through the cancer treatment, they felt they were not living up to expectations around them and being marginalized with respect to their own experiences. Thus, many found it quite difficult to ask for help or support. In this context, the cancer survivors in this study also reflected on how their survivorship experience was further influenced by a number of contextual factors associated with ideas and attitudes within the cancer care system.

5.4 Encountering the Legacy of the Pre-Diagnostic Phase

The first such factor was the legacy of the pre-diagnostic phase. Many of these study participants drew links between events that had occurred in earlier parts of the cancer journey and what they were encountering in survivorship. A number of participants recounted how those first visits with primary care providers, diagnostic technicians and the diagnostic environment had shaped ongoing expectations and experiences across cancer treatment and well into the survivorship phase. Some of these initial experiences in the pre- and diagnostic period were described as physically and emotionally threatening. Examples included undergoing breast biopsies with little to no pain medication, primary care providers who consistently failed to acknowledge their concerns about ongoing pre-diagnostic symptoms, and lack of access to cancer-specific health care providers or services that could address their concerns and support their unmet needs throughout the diagnostic period.

Some participants described this pre-diagnostic period like “a black hole” that was reflected on in later phases of the cancer trajectory, including the survivorship phase, as triggering “a PTSD experience.” In some cases, participants felt that these initial experiences had set an underlying foundation for ongoing mistrust and fear that their needs would not be met throughout the rest of the cancer journey. Some of these individuals recalled feeling re-traumatized after the end of primary treatment, where they were being “abandoned” once again from the support of the cancer treatment system and expert cancer care providers. One woman, who had difficulty getting her primary care physician to acknowledge her concerns about her growing breast lump pre-diagnosis, recalled having similar fears and concerns after primary treatment ended with new, related worries about fear of cancer recurrence. She began experiencing nightmares in the post treatment phase that reminded her of her early experiences yet did not have access to support to develop helpful coping strategies to manage those fears that built on her earlier experiences. She

stated, “I was hoping to create a sort of mystique between my early experiences and the after cancer life ... I was having cancer reoccurring nightmares.”

The treatment phase of the cancer journey also included points where participants described impacts on their later survivorship experiences. For example, some participants reported occasions in which it seemed apparent to them that their clinicians were basing recommendations on immediate cure considerations without an apparent regard for their quality of life or future life goals. Looking back on their cancer journey, many participants identified treatment decision making as an aspect of their care where health care providers did not make it clear regarding the impact of late and long-term effects that the individual might experience post primary treatment completion. Others recounted how their oncologist and other clinicians steered discussions during treatment decision making to focus solely on how their cancer was likely to behave, and did not include information or insights on how the treatment might impact their lives post treatment. As a result, informed consent was based on a narrow understanding of the implications of that decision, which affected their survivorship experiences. Some participants expressed regret about their treatment decisions because of how it affected their life long term. For example, a young woman three years post breast cancer treatment explained,

I think they should have explained to me the possible side effects, more. I didn't get any of that [lymphedema] information prior to agreeing to do the radiation. So that was like kind of one part I really regret to this day. It was like being convinced to do the radiation. Now I'm still living with the effects of the radiation which, you know, has really messed me up... My range of motion is really limited. I've a lot of pain and that's caused by radiation.

Another young woman treated for breast cancer reflected on how a lack of discussion with her oncologist about the impact of her treatment on her future fertility and career in the post treatment

phase of her life created a sense of anxiety and distress. Even in retrospect, she described feeling a tension between prioritizing decisions about lengthening her life over considering other important individual values and goals for her future, such as becoming a mother and having a successful career. She described the tensions between focusing on her cancer and being a young woman with career and family aspirations, yet these important life goals were not optimally woven into her treatment decision support provided by her oncologist.

The oncologist's focus is mainly treatment of the cancer and not so much peripheral... you know, the other issues that we have that would affect the individual...they want to treat the cancer and obviously that's what they're there to do but I think fertility and career are what your life is centred around when you're this age. I don't think practitioners are used to having to like talk about how treatment would impact those issues which are two of the biggest issues, I think, for this age group...So you're trying to like save your life in one way but in also another way you kind of have to like give up on like these other things.

Thus, the idea of the experiences of the prediagnostic phase coming to centre stage again at the time of transition beyond the primary active treatment phase highlights that this may be an important area for continued reflection.

5.5 Prioritizing Disease and the Physical Body

I'm not a tumor...that's how I see it. I'm a person.

Another feature of the participants' accounts had to do with the system and professional focus on the biological and physical aspects of what they were experiencing more holistically. The largely singular focus on cancer as a disease, without also considering the holistic needs,⁵⁷ had an impact on their adaptation and self-management after treatment completion, resulting in

⁵⁷ Holistic needs include emotional, psychological, practical, social, spiritual, informational and physical needs (Fitch et al., 2008).

negative experiences for many participants during the survivorship phase. Many participants described feeling that their access to survivorship care was prioritized according to the presence/absence of disease, as well as severity of disease. For example, when one's cancer was in remission or cured, and there was little or no disease to focus on, many participants reported feeling shut out of the cancer care system. In some situations they interpreted this as signaling that they were not worthy of health care providers' attention. One 64 year-old woman post breast cancer treatment reflected on not being able to access her oncologist to discuss ongoing long term side effects and fear of cancer recurrence concerns, saying, "I'm no good to you because I don't have cancer...nothing new [stable disease]...so you kind of feel you are not important...Being healthy [biologically] is sort of an anomaly."

Although most participants reported feeling relieved that their cancer was in remission or cured, the implications their new disease status had on their access to health professionals with cancer expertise in the survivorship phase created a new layer of distress and worry. These participants reported ongoing concerns about how to manage late and long term effects, fear of recurrence concerns, sexual health challenges and return to work issues, to name a few significant ongoing cancer-related concerns in the post primary treatment period. While many participants felt jubilant to achieve a remission or cure post-primary treatment, the cancer survivorship system structure created challenges for them. The setup of the cancer survivorship system which prioritizes access to care for physical needs and disease surveillance over holistic needs left many feeling abandoned, alone, and unable to optimally adapt to this new survivorship phase of the cancer journey.

The positioning of one's stage and grade of cancer in relation to others was another factor described by study participants that influenced their survivorship experiences. Some participants commented that they felt their own cancer was less advanced or not as serious in comparison with

others. As one woman commented, “I’ve said to many friends that in the cancer world I’m a small potato. I recognize that, you know, it wasn’t a massive tumor.” Across many interviews, participants talked about how they felt less deserving of care post treatment as the seriousness of their disease decreased. Participants with early stage cancer (and therefore curable disease) commonly described feeling less deserving of supportive care post treatment completion, even when they continued to have common unmet needs such as late and long-term side effects, sexual health concerns, and return to work issues. Many of these early stage cancer patients also talked about how their peers with more advanced cancer should have priority care during treatment and beyond. However, this prioritizing of advanced disease stage and grade also posed challenges for some participants. For example, the woman who referred to herself as “a small potato” also remarked that the size or severity of her disease should not be the primary measuring stick for access to cancer care expertise, even beyond the end of primary treatment. Instead, she suggested:

I appreciated the oncologist... she obviously knew it [the tumor] was small and I’m sure she’s with much larger cases all the time and palliative cases...I’m a small potato. But they should be respecting me as a patient, and including the physical needs and I can’t emphasize enough, the emotional needs as well...these continue after treatment is done. In my world, I’m a big potato. This is my first and only experience and medically it’s been the most traumatic thing of my life.

Other participants remarked on how the oncologists’ educational preparation and world view may perpetuate the primary focus on cancer as a disease, and away from seeing the person first, with many holistic needs that may be impacted by living with cancer. Although the oncologist’s focus on curing cancer was important to participants, some came to feel that this focus was too narrow and did not include elements of health promotion and enhancing wellbeing. This narrow,

disease-oriented focus impacted the relationship that some participants developed with their oncologist over time. One woman explained,

I couldn't really connect with my oncologist... in medical school they probably don't study diets or being healthy... like fitness and diet... wellness. I felt that they focus really on the tumor and just the tumor. Very, scientific and everything under the microscope. I believe in more systematic healing, that my emotion and my spirit has an effect in the cancer growth and in the healing of myself.

Some participants also remarked on how their interactions with physicians made them feel as if they were being addressed in pieces, with certain body parts more prominent than others. This sense of fracturing into body parts made some feel that they were not seen as a whole person, and that their beliefs, values and goals as a whole person therefore were not important or of value to the treatment decisions. One woman summarized,

Yeah it's very fractured... people are chopped up into little bits and pieces and you... you are not a person. You are a breast right now and no one looks at the whole person. They don't address that there is a person here who must be going through a lot of stress. It's, it's just... you're disembodied, you're completely just chopped up.

Thus, this idea that the cancer care system focused its attention on responding to certain cues of biology and physiology but not the more holistic experience of the patients who were living with the disease was pervasive through the transcripts of these cancer survivors.

In relation to this prioritization of the biological and physiological components of their overall cancer experience, these patients recognized that the perspective of the physician dominated that of other health care professionals involved in their care and that physician perspectives on what constituted priority issues continued as they transitioned into survivorship. It seemed apparent to the cancer survivors who contributed to this data base that the primary driver of the decisions

with respect to the care that was or was not offered to them was the physician. Despite a current national focus to include patients and families as partners at the centre of all models of care (e.g., CPAC, 2012a), many individuals reported interactions and experiences with health professionals and care systems/processes that placed their own perspectives on the “outside”, minimizing their capacity to influence care processes and outcomes. For example, survivorship care plans (SCPs), although intended to provide a personalized care plan post treatment that also includes one’s goals for health, rarely involved the participant’s input. In fact, many participants didn’t even know a survivorship care plan existed, and if they were aware, they did not expect to have input. When asked about his SCP, a 67-year old participant with GI cancer said, “I never saw any [survivorship] care plan... I think this is just for the doctors.”

5.6 Interpreting Hierarchical Dynamics

In that the original study for which the data base had been constructed was explicitly concerned with patient perspectives on communications (both helpful and unhelpful) between them and their professional health care providers, many of the reports associated with challenges in the survivorship context focused on tensions within these communications. In many instances, these study participants associated challenging communication between them and their oncologists with a perceived power hierarchy. In several instances, they explicitly attributed a negative impact on their survivorship experience to these perceived power imbalances.

Participants described numerous challenges, including: understanding the medical terminology; making their beliefs, values and goals clear to the oncologist; gathering enough information to make an informed decision; and feeling that their oncologist supported their treatment decisions, regardless of whether or not it included prescribed treatments. One woman who experienced significant long-term radiation-induced side effects post treatment reflected on

how her oncologist influenced her decision to undergo radiation despite having reservations about this treatment from the start:

I think if you have a difference of opinion from your oncologist you have to work very hard to push that because you just pretty much have to go with what they say... it's kind of like I feel I deferred to them because they are the experts, they're the doctors. What do I know? Like I don't know, I'm just the patient and if I had a difference of opinion I feel like I can't trust myself more than I trust them; maybe if I had been more informed particularly about the radiation I would have pushed my decision on that more but I wasn't informed. ... that's the regret I have not being informed enough about that.

In this example, the participant highlighted the tensions that can exist between the oncologist's expert knowledge and the patient's beliefs, values and goals. The woman described herself as "just the patient" and indicated that the oncologist's expertise held a higher stake/more power in influencing treatment decisions. Another participant, an older prostate cancer survivor, described feeling that he didn't have sufficient knowledge of what symptoms and side effects he should be watching for post treatment. He highlighted the power difference in the physician-survivor relationship, and how this impacted how he did not feel he had the right to press the oncologist for information to address his own learning needs:

I tend to be rather curious and I would have been interested in knowing what exactly he was going to be watching for in the next two years but, you know, I'm his patient. He's not my patient and so I didn't press him....It's his business to inform me. It's not my business to be ...constantly drawing information out of him.

For some participants, the positioning of the physician as driver of care had positive benefits. One example of this was when a physician strongly encouraged a young woman post breast cancer treatment to attend a supportive care retreat for young cancer survivors. Although the

young woman did not initially want to attend, the strong suggestion from the oncologist resulted in long lasting positive impacts on the survivor's mental health and supportive connections with like-minded peer survivors.

And so my first appointment after treatment with her [new oncologist], she asked me if I would like to go to this retreat... which was incredibly helpful and it really, I think as far as survivorship goes, changed my life because before I joined that group I really felt isolated and I didn't really want to deal with any of the issues that came with having had cancer and I reluctantly went to the retreat and it really opened up a whole new community for me; so that was really great and I'm still active in that community so that was probably the best thing that she did.

In this example, the oncologist had come to understand the participant's beliefs, values and goals, and gently used her physician-held power to influence the young woman to engage in the retreat.

Perceived power hierarchies between primary care providers (e.g. general practitioners/family physicians) and oncologists also surfaced in the accounts of these participants. Rather than a coordinated transition from one provider to another, some patients were aware of considerable inconsistency within the system. A prostate cancer survivor who actively participates in a prostate cancer support group made this observation:

Reflecting on my experiences with the many men who participate in our support group, there seems to be a hodge-podge approach by medical practitioners to this transition. Some urologists provide patients with the information and support they need for transitioning from patient to survivor and some simply hand off the patient to the GP with little or no support. GPs are not always well equipped to address this concern and have limited time.

Several participants described having a greater degree of trust in the advice of specialists over generalists. For example, a young woman with osteosarcoma explained that she saw oncologist as having more knowledge and power to ease her concerns that her post treatment disease surveillance test results were not worrisome. She said, *I trust my GP to tell me my [follow-up] test results, but I'd feel better if my oncologist got the results too and confirmed that everything is still status quo.* Another older leukemia survivor also reflected on how his relationship with his general practitioner was different from his oncologist due to the level of specialized knowledge and expertise of his oncologist. He said, "It's a different relationship [with a GP] than with these cancer specialists... GPs don't really have... they simply can't know enough... With a GP it's quite different. It's not quite so advanced, if you will". Although survivors perceived that it was reasonable post treatment to expect less access to oncologists and/or oncology nurses as these health professionals have to focus on patients receiving treatment, many also acknowledged that they may have ongoing fear of recurrence post treatment, so that ongoing vigilance by an oncology-focused health professional would help allay their fears and concerns. A younger woman post breast cancer treatment reflected,

It's hard when they let you go, 'cause you feel like you've been watched so closely for so long and then all of a sudden, you're supposed to be fine but I think, like psychologically, there's always the fear of recurrence. So, I'm not sure how to address that like if... I mean, they're so busy with their patients... it's understandable that they don't have time to deal with survivors... and I guess that's why the Callanish or YACN support groups are good.

A final form of hierarchical dynamic that some of these survivors recognized was that there were fundamental structural inequities in such issues as access to resources and support. Patients whose cancers were of a more common variety (especially breast and prostate) were far more

likely to have access to support groups and resources than were those with less frequent or survivable cancers. Younger patients were highly sensitive to how much within the cancer system sensibility was geared toward the more dominant population of older patients. Their accounts also highlighted a number of subtle nuances with respect to different experiences for those with serious versus more “minor” cancers and the degree of curative success of their particular disease. These kinds of issues played out in an awareness of which patients would be treated with more importance within the system, who would have ready access to resources and supports, and who would be left struggling to get their needs met.

Thus these various ideas with regard to who was more or less informed, influential and knowledgeable seemed a matter of considerable concern for many of these patients, in that they felt they had to make choices and navigate between different kinds of experts and different forms of expertise. For many, this was experienced as an issue of power, with the power being held most strongly by the oncologist, with the primary care physician having some measure of authority, especially once primary cancer treatment was completed, and the patient/survivor having very little power at all with respect to such important issues as plans for survivorship care. They were mindful of whose opinions held most weight at various stages, both within the system and in relation to their decision-making. And although they generally assumed these hierarchies were grounded within rational explanations, they also did recognize that power dynamics were at play.

5.7 Finding a Way Forward

In order to move forward into their survivorship, many of these study participants felt a strong need to know what path they were on and to feel that it was laid out in a manner that would respond appropriately to the way in which their cancer behaved over time. As one man explained,

For me having, knowing where we are at all times is important, you know in, in the process and now it's, you know even, even now when I see doctors from time to time, you know, they're still pretty guarded about my prognosis, about how long I'm going to stay in remission.

For several of these study participants, a sense of relative security required that they feel “visible” within a system of care. This was especially important at a time when fears of recurrence were high and support from health care professionals might ease this fear. One woman described her experience of finishing primary treatment this way. She said, “You feel all alone and no-one is checking on you... I felt really paranoid like cancer is going to come back but no one is watching me. I am invisible.” Another man, a 77 year-old with GI cancer, felt that, although a written record might be serving the function of communication between the parts of the system, he did not feel a part of that communication.

They [doctors] communicate with the chart, like, to me, through the chart... I'm there as the object of their curiosity and to fill in the blanks when my story is not clear in the chart... I've been handed off, my life story contained in the chart.

Another confirmed that the shift from being actively managed through treatment into this next phase of cancer was very much missing that human connection. “I see big chunks missing, that it's very impersonal. It's been dehumanized, that there is not a person here.”

As time progressed away from their final treatment, many survivors talked about the tensions between wanting (and at times needing) access to expert care post treatment, but at the same time, trying to put their cancer experience in the past. A number of their accounts suggested a process of hanging on and letting go, both on the part of the oncologist, and the survivor. In some instances, if the survivors clearly asserted their needs, the professionals within the system would respond in a manner that seemed supportive. One older woman survivor of breast cancer

recounted how both her own needs and her oncologist's expertise were integrated to develop a pathway for re-accessing specialized survivorship care. She said, "She's [oncologist] extended me to six months [follow-up]...she's extended my leash...initially ...there was sort of a bungee cord that she used, as a doctor and I don't feel that so much anymore, as matter of fact."

Similarly, an older man post leukemia treatment described how he set the pace for slowly letting go of the specialized cancer expertise over time:

I don't feel quite as...I don't feel as tied to the bone marrow people as I used to. It's nice to see them and it is reassuring to know that they are there in the background, so I think that is probably the extent of it right now. I am letting go a little bit more.

Some survivors also described the need to integrate with other survivors as a strategy to manage post treatment. Through support groups and other networking events, survivors were able to collaborate with peers and support each other through challenging post-treatment.

Within their accounts, the study participants shared numerous recommendations for what they thought would make sense as system responses to the distinctive needs of a growing population of cancer survivors. Some felt that support groups should be formalized and made more accessible. Others envisioned online resources that were individualizable yet credible and reliable. "There's no one here to guide us or steer us or give us even a list of, you know, websites that you might find useful. It's like we're just completely left on our own." Others felt that there ought to be a backup option if cancer survivors were unable to attract a sufficiently enthusiastic response from their primary care provider when they had concerns that could potentially be recurrence related, as one woman's account illustrated:

About 6 months after my treatment, I felt bone pain around my rib cage. I was deeply concerned. I tried to reach my oncologist three times and left him messages but he never

returned my calls. I later went to my GP for help. She told me that I must be paranoid about cancer.

Some suggested that perhaps there ought to be drop-in options at the cancer centre, or some mechanism whereby a patient could resurface within that system without a referral. A few thought that there would be great benefit in having some kind of resource or service that would help them interpret and make sense of probability statistics as their situation changed over time. Some survivors who had found their way into cancer rehabilitation services thought that fitness trainers and nutritionists should be widely accessible, given the benefit they provided. Others focussed on return to work supports, including permission not to feel guilty if they were unable to return to work on a full-time basis. Others envisioned a more easily accessible counselling support system. “Almost a place where you could say, here’s a number you can call in a few weeks, you know, acknowledging this is definitely a very difficult time.”

Overall, most patients felt that the transition to survivorship was sufficiently complex and predictable, even though individual features may differ between patients, that it ought to be provided for in an anticipatory manner. They believed that the more fulsome life issues that had been affected by the cancer diagnosis, experience, and treatment required attention, and that it should not be left to the patients alone to figure it out. One colorectal cancer survivor’s reflections, presented here in an extended excerpt, seems to capture that sense of both the need and the possibility that was such a prominent theme across all of the survivor accounts:

I know, I’ve, I’ve thought about this over the last year. Like what if... what would it look? Like, if I could have created something, what would it look like? It wouldn’t be the oncologist who would have done this, I don’t think. I think it would be almost more like a, like a counselor or a psychologist or... I don’t even think the nurses or doctors, that’s so much their job because they have their jobs, you know but maybe having like... I don’t

know however many you need whether that's one, two, three or however. I just think you need to talk about your experience after or you just need to debrief. ... Well obviously, everything in life should be a choice but I almost think that they should book an appointment 'cause they book appointments for everything else. They book for blood, they book for scans, they book for chemo, they book for radiation whatever. Book me that last appointment. After my last chemo treatment, I want to have an appointment. I don't know if it's an hour, if it's a half hour and if it's like, once a week for a month, I don't know how long it's going to go on or what the periods of time would, would be but I would like. I would have loved to talk to someone afterwards and I would have loved that someone whether it was a psychologist or a counsellor, whoever to just kind of give me a heads-up. Like let me know that if you feel depressed, it's... that's totally normal. Like you're not going to... like I, for three and a half weeks, I couldn't get out of bed and I just... and I cried almost every single day and I just... like I just fell apart after being so strong, you know. And I think I really needed someone to just tell me that these things may happen. Like you may feel depressed, you may feel completely, ridiculously, vulnerable and you may feel like you're totally out of control. You may feel like, like I didn't work for a year and a half and you know. ... It's everything, your money situation, your health, you look like crap, you know It's just a bit of everything.

The survivors in this study were acutely aware of the efficiency drivers within the system that precluded the opportunity to combine psychological support with the informational expertise they depended upon.

To me it means that they don't want to talk about it. It's like they don't have time to have someone get upset in their office and they might run overtime, you know, 'cause you can't tell somebody to get out of your office. So just don't go there. It's like don't break the

seal, right and you know, once you do that and the emotions come out and maybe this person needed another five minutes of your time which you don't have.

They were also sympathetic to the enormity of the burden on the hard working oncology professionals who had provided. Many of them fully accepted that they had to take responsibility for being their own navigator in a system that was far from integrated and coordinated.

“Ultimately, it’s like I’m responsible for putting together my own healthcare team....The clock is ticking all the time and it’s like you don’t really think that you have the luxury of time, but yet the healthcare system seems to be quite fractured to me. It’s a bunch of parallel rows but none of them seems to connect.” In addition, they were fully appreciative that they resided in a major urban centre where geographic access to system resources was exponentially better than would be the case if they had to travel long distances to obtain their cancer care and survivorship care, or to rely on less specialized local resources.

Finally, interspersed throughout the accounts of these cancer survivors, perhaps because of the focus of the original study on communication in cancer care, were numerous accounts, both positive and negative, with respect to relational care. Again and again, their recollections reinforced the importance of relational care in the context of a cancer illness, and the exceptionally positive experiences they had when their relationships with health care professionals were such that they felt respected, valued as a unique and important person, and that the professional actually cared.

Like most doctors just walk in, talk results, check you out, go. He actually like pulled up a chair beside me and sat down and we would chat, you know. And he was still business, but he just... just made me think, God you know, here's a guy who's going to spend more than just those five seconds of walking in and walking out. He's going to sit down with me and it just makes you... feel validated. It makes you feel like you're a person. It makes

you feel like they care enough about you to spend that time and the effort, you know and it just makes me trust them a lot more.

Whatever challenges they might face within the systems and structures of care as they transitioned from active treatment into survivorship, meaningful relationships with their health care professional providers could go a long way to filling the gaps and guiding their process forward.

5.8 Phase 2 Summary and Key Insights

This set of findings has provided an overview, based on an extant data base consisting of interviews with patients reflecting on their transition beyond active cancer treatment, of some of the dimensions and issues that shape their survivorship experience. Although survivorship care was not a focus of the interviews, the accounts very clearly demonstrate the importance it holds for these patients and some of the challenges they encounter entering into and moving forward with life as cancer survivors.

Secondary analysis has inevitable limitations, in that one is restricted to what exists in the text and cannot probe for further detail or elaboration on a theme. However, as these findings confirm, it can be a helpful component of a larger study, providing the researcher with a preliminary grounding in the look and feel of how persons in a certain situation experience and interpret it. It can help move beyond the expected categories of what human accounts might look like and demonstrate the interconnectedness and intersectionality of complex human experiential phenomena. In this instance, the available data set certainly confirmed the relevance of this work in trying to untangle the challenge of survivorship and also created a sense of humility that there will be no straightforward answers. However, recognizing the generosity of these patients in sharing their stories and trying to propose constructive and creative solutions, the analysis does

seem to suggest that the work is worth doing, and that the wisdom of both patients and system planners, including policy makers and clinicians, will be required.

These findings provide an understanding of the kinds of possible themes and issues that will guide the exploration in Phase 3, the survivor and stakeholder interviews, as we continue to try to unpack the complexities associated with what those who live with through and beyond cancer consider acceptable and necessary in terms of survivorship care, and what constitute inequities in access to or quality of survivorship care from their perspective.

Through these accounts we have had a taste of the societal meta-narratives about cancer and cancer recovery that can create unnecessary added tensions and distress for some survivors. We have also heard what it feels like to focus on eradicating or controlling disease without considering the impact of treatment on life after cancer. Within the accounts, we hear echos of possibilities such as doubt, regret, depression, and ongoing uncertainty that may leave some survivors and their families with a dramatically reduced quality of life after cancer, regardless of the physiological, structural or biochemical effects of cancer and its treatment.

The patients in this sample clearly felt strongly that their personhood and preferences ought to have a meaningful place in the systems of care into which they transitioned after active cancer treatment. They felt that their beliefs, values and goals ought to be integrated into the care approaches. As Sanders et al. (2018) argue, “when we fail to provide care that matches patients’ preferences, we commit a medical error, no less urgent than any other harmful error” (p. S17).

The implications of these ideas, and the role they play in relation to eventual suggestions for advancing toward a preferred future in cancer survivorship care, will be further developed in conjunction with the insights that arise in the interview portion of the study, where both cancer survivors and those who devote their professional lives to addressing the challenge of cancer survivorship will weigh in on these complex and fascinating questions.

CHAPTER SIX: Findings from the Survivor and Stakeholder Interviews

6.1 Introduction

Over an 18 month period from spring of 2016 through fall of 2017, informed by findings from the critical documentary analysis as well as the secondary analysis of transcribed material from the CCC study in fine tuning my inquiry process, I conducted 34 interviews with cancer survivors and 12 with cancer survivorship system stakeholders. Constant comparative analysis, facilitated by periods of immersion interspersed with periods of reflection throughout this period ultimately yielded an evolving matrix of key observations and insights relative to the research question.

A vast quantity of material in the form of transcribed interviews, all coded and sorted into NVivoTM qualitative software, as well as field notes and analytic notes, was compiled over this period. Over multiple supervisory meetings, the implications of various structures with respect to organizing and displaying the key highlights of this material were considered and a preferred structure was arrived at that would optimally display the most relevant and intriguing insights arising from the findings, and illustrate those insights with exemplars drawn from the verbatim transcripts.

As has been explained in the preface to this document, health issues arose that precluded the preparation of an expansive narrative report of the findings as intended. However, the analytic thinking that resulted from that period of immersion in data collection and analysis is clearly apparent in the organizing framework that had been intended as a guide to the actual writing, and that will be presented here in the form of notes and bullet points. It is hoped that some of this material may find its way into publication at some point in the future.

The survivor interviews were dominated by accounts of how their expectations for cancer survivorship care failed to match that reality, and a close examination of the nature and nuances of those gaps, and the way the study participants made sense of them, was a key feature of their accounts. An overview of this gap, from survivors' perspectives and later from stakeholders' perspectives provides an entry point into the data that describes some of the key issues that may be a result of the system and other structural and contextual factors that have shaped these experiences and expectations.

6.2 Survivors: Overview of Individual Experience Issues

Gap: While some survivors report their “survivorship” needs being met (expected = what they received), most describe gap between actual and expected survivorship care

Expectations: Most expected to receive person centred, individualized, holistic care; ongoing relationship & reciprocity with their health care providers; some expectation for self-care but also expectation of health care provider(HCP) support to optimize self care, etc.

- Some expectations of survivorship care are shaped by rural/remote status (expect less access, quality, etc.); disease status (“non curable” or rare/complex cancers expect less); previous experience with cancer treatment system (those with bad experiences expect less or do not trust HCPs within survivorship); those with knowledge/resources for self care expect less of system; etc.

Experiences: Most survivors experience:

- **Cancer as a chronic disease;** “cancer survivorship is forever” (yet survivorship system of care focuses on transition immediately post primary treatment and/or episodic acute “problem-focused” care)
- **Finding “the new normal”** after treatment is difficult; complexity of holistic ongoing needs; rarely are needs beyond disease surveillance met. Key unmet survivor needs that negatively impact quality of life include, for example, fear of recurrence, return to work, etc. New normal is impacted by developmental ages and stages (e.g. AYA have different priorities than retired people).
- **Work of survivorship** (survivor as pivot/navigator; self-navigation through system without supports)
- **Communication** about survivorship care is generally between health care providers, bypassing the survivor; communication is largely based on disease-focused aspects of care (e.g. survivorship care plans that do not invite input from the survivor; secondary cancer screening, disease surveillance as goals in survivorship care)
- **“I don’t fit the mould”.** Generally, anyone outside of the “typical” cancer survivor, for whom the nascent survivorship system is designed, is further marginalized. E.g. complex needs; concurrent chronic health conditions; rural/remote; AYA or very old; experiencing marginalizing conditions that impact SDH; language other than English; any cancer outside of breast, scapacity for self-care; etc.
- **Social determinants of health.** Little to no attention to the SDH, which further impacts those who experience marginalizing conditions within society (e.g.

woman on income assistance with radiation induced pelvic side effects must pay out of pocket for restorative physio; woman (65+) living in northern BC must get job post treatment to cover costs associated with travel to specialist care, yet is experiencing sig. long term side effects; young woman who does not fit heteronormative/older adult survivorship care structures is unable to find optimal social support for her recovery post treatment, etc.)

- **Lack of trust or confidence** in their health care providers and the system in general, due to being made to feel that they don't belong, are dismissed, are made to feel there is one way to "be" within the survivorship system and anything outside of this is asking too much.
- In this study, **survivors who report having their needs met** are typically 50-70 yr old women with curable breast cancer, urban living, high SES, good extended health benefits and back to work supports, good social supports, huge capacity for self care and self advocacy, few lingering side effects of treatment, access to survivorship resources and supports (e.g. peer, cancer-focused exercise programs, etc.), good relationships with their primary care provider, etc. (The system was designed for these people).

6.3 Stakeholders: Overview of System Level Issues

Group/population – stakeholders talk about the gap between groups (i.e. inequities between groups) as problematic –

- How we set up the “**measuring stick**” **between groups** is problematic – We are always measuring one group against a standardized “norm” to determine inequities; this comparison and expectations may in fact marginalize the Other.
- Intersecting influences of colonialism, biomedical model including EBM, lack of consideration of SDH, tumor group driven “norms”, survivorship guidelines that are not inclusive of a diversity of people, etc.
- Solution is not looking at “equity groups”. Investing in equity groups alone may not give us long term solutions. Must think about impacting systems that do not compare groups, but instead **strengthen people to reach their fullest potential in a group** (without necessarily comparing them to others).

6.4 Understanding Barriers to Equity in Survivorship Care

Drawing on both survivors and stakeholders to better understand what some of the most troubling barriers seem to be.

Barriers from the Survivor Perspective: Each of these barriers has multiple layers and many of the barriers intersect and layer to create greater issues. Also, some other factors (e.g. communication and relationship) may help to mitigate some of these barriers. I am working on conceptualizing and synthesizing these and other barriers; there is a plethora of data from survivors and stakeholders about system problems and recommendations for improvement

- a. Biomedical model
 - i. Disease focus – curative focus
 - ii. Cancer as an acute, episodic illness

- iii. EBM; guideline driven
 - iv. Treatment focus (at expense of health promotion and wellness)
 - v. Population focus; “Average person Focus”
 - vi. Diversity and context are stripped from population norms – survivorship guidelines are developed based on this
 - vii. Focus on physical needs at the expense of emotional, psychological, spiritual, informational and other holistic needs
- b. Power hierarchy - among and between care providers, survivors, families, peers, etc.
 - c. Colonialism – privileging Eurocentric population based norms to define “standards” in survivorship care.
 - d. Ideology of Scarcity
 - Efficiency drivers- overarching goal is to streamline the system and create efficiencies to save money. This may not align with high quality survivorship care for all.
 - e. Funding structures
 - Physician and (extended) health insurance reimbursement structures
 - Resources for “cancer care” tied to treatment (does “cancer care” include survivorship? Need to influence policy too)
 - f. Research drivers (e.g. political influences; biomedical models; efficiency drivers)
 - g. Siloing – obscures overall perspective
 - Inside/outside conventional care
 - Specialty knowledge and services within the health care system

- Care organizations
 - Survivors/families and HCPs
 - Siloing of the survivor. i.e. break person down into body parts, symptoms, etc. obscures holistic focus and contextual understanding of survivor and their needs.
- h. Metanarratives. i.e. gender, women’s bodies, cancer, survivor, good patient, caring compassionate doctor who knows best.
 - i. Minimal focus on SDH – system and resources are designed for population norms; access to system and resources are constrained when SDH are not considered.
 - j. Variable interpretations of person centred care, patient empowerment, etc. that do not match survivors’ interpretations. The tension between biomedical model and person centred care become apparent.
 - k. Etc.

Barriers that Become more Apparent When you Add the Stakeholder Perspective

Problems lie in the structures, context, factors within “the system” that shape individual and group/population experiences, expectations, and outcomes.

- Overall, there is a sense of “**institutional arrogance**”. i.e. thread of paternalism that runs through survivorship models, system, resources, etc., where the system is dominant and the HCPs within it are afforded more power than the survivors. Although there is language of person centred care, patient empowerment, etc., the structure of the survivorship system does not easily support this, and can create more challenges for survivors to achieve equitably high quality survivorship care. Instead of the system flexing to their needs, survivors must flex to the system.

- We can and must address “system” barriers and foster strengths that influence equitably high quality care at individual and group/population levels. Need to conceptualize the barriers (and strengths) so that they may be best understood, organized and taken up as recommendations for change/action.
- Need to highlight the tensions:
 - Biomedicine/EBM and person centred care
 - Individual and group needs
 - Siloing of person/system/specialization and holistic, person centred care.

6.5 Understanding the System Strengths as Potential Mitigators to the Barriers

Drawing on both survivors and stakeholders, we can better understand what system strengths there are to work from as we strive toward high quality and equitable cancer survivorship care

System Strengths and “Mitigators” (i.e. ease the burden of the system structures on survivors)

- Communication, relationship and reciprocity with HCPs (flattens hierarchy, promotes person centred care, improves continuity of care, etc.)
- Primary care provider maintains connection with survivor from diagnosis onward
- Access to cancer expertise post treatment
- “Appropriate” peer support (groups, 1:1, online, telephone, etc., aligned to unique experiences and needs – not necessarily tumor group)
- Cultural safety/sensitivity
- Self care capacity of survivor (resources, knowledge, geographic location, etc)

- Palliative approach to care (knowing that survivor has a team to care for them regardless of how their cancer behaves)

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- How we set up the “**measuring stick**” **between groups** is problematic – We are always measuring one group against a standardized “norm” to determine inequities; this comparison and expectations may in fact marginalize the Other.
- Intersecting influences of colonialism, biomedical model including EBM, lack of consideration of SDH, tumor group driven “norms”, survivorship guidelines that are not inclusive of a diversity of people, etc.
- Solution is not looking at “equity groups”. Investing in equity groups alone may not give us long term solutions. Must think about impacting systems that do not compare groups, but instead **strengthen people to reach their fullest potential in a group** (without necessarily comparing them to others).

6.4 Understanding Barriers to Equity in Survivorship Care

Drawing on both survivors and stakeholders to better understand what some of the most troubling barriers seem to be.

8. **Barriers from the Survivor Perspective:** Each of these barriers has multiple layers and many of the barriers intersect and layer to create greater issues. Also, some other factors (e.g. communication and relationship) may help to mitigate some of these barriers. I am working on conceptualizing and synthesizing these and other barriers; there is a plethora of data from survivors and stakeholders about system problems and recommendations for improvement
 - a. Biomedical model
 - i. Disease focus – curative focus
 - ii. Cancer as an acute, episodic illness

- iii. EBM; guideline driven
 - iv. Treatment focus (at expense of health promotion and wellness)
 - v. Population focus; “Average person Focus”
 - vi. Diversity and context are stripped from population norms – survivorship guidelines are developed based on this
 - vii. Focus on physical needs at the expense of emotional, psychological, spiritual, informational and other holistic needs
- b. Power hierarchy - among and between care providers, survivors, families, peers, etc.
 - c. Colonialism – privileging Eurocentric population based norms to define “standards” in survivorship care.
 - d. Ideology of Scarcity
 - Efficiency drivers- overarching goal is to streamline the system and create efficiencies to save money. This may not align with high quality survivorship care for all.
 - e. Funding structures
 - Physician and (extended) health insurance reimbursement structures
 - Resources for “cancer care” tied to treatment (does “cancer care” include survivorship? Need to influence policy too)
 - f. Research drivers (e.g. political influences; biomedical models; efficiency drivers)
 - g. Siloing – obscures overall perspective
 - Inside/outside conventional care
 - Specialty knowledge and services within the health care system

- Care organizations
 - Survivors/families and HCPs
 - Siloing of the survivor. i.e. break person down into body parts, symptoms, etc. obscures holistic focus and contextual understanding of survivor and their needs.
- h. Metanarratives. i.e. gender, women’s bodies, cancer, survivor, good patient, caring compassionate doctor who knows best.
 - i. Minimal focus on SDH – system and resources are designed for population norms; access to system and resources are constrained when SDH are not considered.
 - j. Variable interpretations of person centred care, patient empowerment, etc. that do not match survivors’ interpretations. The tension between biomedical model and person centred care become apparent.
 - k. Etc.

9. **Barriers that Become more Apparent When you Add the Stakeholder Perspective**

Problems lie in the structures, context, factors within “the system” that shape individual and group/population experiences, expectations, and outcomes.

- Overall, there is a sense of “**institutional arrogance**”. i.e. thread of paternalism that runs through survivorship models, system, resources, etc., where the system is dominant and the HCPs within it are afforded more power than the survivors. Although there is language of person centred care, patient empowerment, etc., the structure of the survivorship system does not easily support this, and can create more challenges for survivors to achieve equitably high quality survivorship care. Instead of the system flexing to their needs, survivors must flex to the system.

- We can and must address “system” barriers and foster strengths that influence equitably high quality care at individual and group/population levels. Need to conceptualize the barriers (and strengths) so that they may be best understood, organized and taken up as recommendations for change/action.
- Need to highlight the tensions:
 - Biomedicine/EBM and person centred care
 - Individual and group needs
 - Siloing of person/system/specialization and holistic, person centred care.

6.5 Understanding the System Strengths as Potential Mitigators to the Barriers

Drawing on both survivors and stakeholders, we can better understand what system strengths there are to work from as we strive toward high quality and equitable cancer survivorship care

10. System Strengths and “Mitigators” (i.e. ease the burden of the system structures on survivors)

- Communication, relationship and reciprocity with HCPs (flattens hierarchy, promotes person centred care, improves continuity of care, etc.)
- Primary care provider maintains connection with survivor from diagnosis onward
- Access to cancer expertise post treatment
- “Appropriate” peer support (groups, 1:1, online, telephone, etc., aligned to unique experiences and needs – not necessarily tumor group)
- Cultural safety/sensitivity
- Self care capacity of survivor (resources, knowledge, geographic location, etc)

- Palliative approach to care (knowing that survivor has a team to care for them regardless of how their cancer behaves)

CHAPTER SEVEN: Discussion, Recommendations & Future Considerations

7.1 Discussion

In reflecting on the findings of this study, I am heartened to recognize that the call for a more person-centred approach to complex challenges such as cancer survivorship is becoming louder and more powerfully felt across the system. Recent documents such as CPAC's 2018 publication *Living with Cancer: A Report on the Patient Experience* bring this emphasis to the fore as a priority strategic direction for future developments in addressing the survivorship challenge. In that document, a shift toward person-centred care means:

1. Expanding from “episodes of care” to an extended care continuum
2. Recognizing that the patient experience is a dimension of quality and empowering patients to be co-designers of care services.
3. Aligning patients' and clinicians' concepts of what a positive experience is.

The report also forcefully emphasized a holistic perspective of what cancer survivors require, beyond attention to their biomedical needs, by including recognition that eight in ten survivors experience physical challenge, including increased fatigue, and changes in sexual function, that seven in ten report emotional concern, including worry about cancer returning, depression and changes in intimacy, and four in ten have significant practical challenges, including returning to work, paying bills and difficulty obtaining health insurance. It also acknowledged that having a clearly designated, accessible, and skilled care provider in charge of their cancer follow-up (whether a specialist, or generalist physician or nurse), made it considerably easier to get help for their concerns. Thus, the ideas expressed in the findings of this study are very much in alignment with what patient advocates and system champions are advocating, and help shed light on the

complex challenges that face us in envisioning how to actually attain the kind of system that will meet the need.

7.2 Recommendations for System Improvement

In order to achieve equitably high quality survivorship care across the cancer care system, these are some of the recommendations that arise from these findings:

Overarching: Conceptual understanding of survivorship/survivorship care

- survivorship starts at diagnosis and survivorship care must be integrated throughout cancer trajectory
- SDH considered across all aspects of survivorship care models, resources, evaluation, etc.
- Person-centred care and patient empowerment definitions must be clarified and operationalized
- Holistic focus of care that includes all dimensions of needs (not just physical).
- Survivorship care HCPs/system must enable survivors to build trust and confidence in HCPs and system.
- Survivors as central to the planning of resources, models of care, etc.

Individual

- Access to oncology expertise and support for survivorship needs when they need it, regardless of geography, SES, cure/palliation, etc.

Group

- Foster strength based interventions for individuals within groups vs. comparing groups.

System

1. Individualized information and resources for survivorship care.
2. Models of care
 - a. Stratified care model based on complexity of needs
 - b. Co-create models of care and resources with survivors/caregivers
 - c. Align appropriate HCPs with survivor needs across cancer trajectory
 - i. Nurse-led survivorship care; place specialized oncology nurses (RNs and NPs) in primary care settings.
 - ii. Models for anticipated needs and urgent survivorship-related needs
 - d. Organize models around survivor experiences and needs; not necessarily disease-focus/tumor group focus.
 - e. Community based survivorship care, including psychosocial care
 - f. Integrate with Chronic illness models of care – interprofessional chronic illness clinics that include cancer survivorship.
 - g. Peer led models
 - h. Return to work programs
 - i. Workplace-based survivorship programs
 - i. Unique models for adolescents and young adults
3. Plan of care that is inclusive of survivors' beliefs, values and goals for care
4. Outcomes measures that are meaningful to survivors
 - a. Metrics include impact of survivorship care on whole person/family
5. Structures to promote communication across silos
6. Better links between cancer treatment orgs (e.g. BCCA) and community resource and support orgs (e.g. CCS, wellness programs, etc).

7. Education of HCPs
 - a. Rural training for all oncology HCPs (unique features of care required when survivor lives in rural setting)
 - b. Oncology training for all GPs
 - c. Cultural sensitivity training for all HCPs
 - d. Communication training for all HCPs
8. Support for HCPs to optimize their survivorship practice
 - a. Community of practice
9. Funding
 - a. Physician re-imburement schedules – optimize survivorship care reimbursement
 - b. Extended health insurance to be more inclusive of survivorship needs
10. Influencing policy
 - a. Advocate for National Survivorship Program to provide national standards, tools, resources, models of care, evaluation strategies, etc.

7.3 Future Considerations

The findings of this study have surfaced numerous questions we still need to ask, and areas of future research or advocacy we need to consider as we aspire toward a comprehensive, high quality and equitable Cancer Survivorship System in Canada. Among these considerations are:

1. How do we disrupt the societal metanarratives about cancer, survivor, and good patient?
2. How do we bump up against or massage the biomedical model and efficiency drivers to minimize the impacts of the Cartesian reductionist underpinnings of evidence-based medicine and the hierarchies within which it is enacted?

3. How do we rebalance the focus to include a diversity of perspectives on what constitutes a “norm”? (e.g. move away from that “average cancer patient’ norm to use a different measuring stick?)
4. How do we use population based guidelines for survivorship care and contextualize them for individuals? Do we need a different kind of tool or resource to guide survivorship practice that is better adept at individualized, contextualized care?

In a report published in early 2018, the Canadian Partnership Against Cancer summarized the challenge of cancer survivorship and the commitment that will be required if we are to aspire to being a nation that achieves its aspirations to provide high quality survivorship care on an equitable basis to all Canadians:

From the moment people start wondering if they have cancer to post-treatment care, the cancer experience is a continuous one for everyone involved. Providing person-centred care during each stage of the journey will ensure that patients and families are seen as unique individuals, receive coordinated care that is considerate of their time and preferences, have access to useful information that promotes self-care, and have their various needs met as they arise (CPAC, 2018)

The ideas that shape our collective understanding of what is needed in the current context to realign our models of care with the needs of the population are in constant change, and it is my hope that some of the insights that have arisen in the course of this project will contribute to that change.

TABLES AND FIGURES

Table 1: Recommendations from the Cancer Patient to Cancer Survivor: Lost in Transition Report (*Hewitt et al., 2006*)

Recommendation 1	Establish cancer survivorship as a distinct phase in the cancer trajectory. Raise awareness regarding the needs of survivors and act to ensure the delivery of appropriate survivorship care
Recommendation 2	Patients completing primary treatment should be provided with a Survivorship Care Plan.
Recommendation 3	Develop evidence-based clinical practice guidelines, assessment tools, and screening instruments to identify and manage late effects of cancer.
Recommendation 4	Quality of survivorship care should be measured through public/private partnerships and quality assurance programs
Recommendation 5	Demonstration projects to test models of coordinated care across diverse communities and systems of care should be tested
Recommendation 6	National cancer control plans should include consideration of survivorship care.
Recommendation 7	Educational opportunities for health care providers to equip them to address the health care and quality of life issues facing cancer survivors
Recommendation 8	Minimize discrimination and adverse effects on employment; support survivors with short and long term limitations in ability to work
Recommendation 9	Equitable access to adequate and affordable health care for all survivors
Recommendation 10	Increase support for survivorship research and expand mechanisms for its conduct.

Table 2: Principles to Guide the Development of Equitable Cancer Care in Canada
(Barroatevena, 2008)

Principle	Description
Integrated person-centered care within well coordinated system of care and services	Physical, psychosocial, emotional, practical, informational, spiritual needs are considered in the development and organization of care delivery services.
Available and accessible supportive care	Some of the strategies under the supportive care umbrella are navigation services. Effective patient navigation strategies are essential to ensure accessibility, continuity and coordination of care throughout the cancer care continuum. Knowledge derived from patient navigation best practices should inform continuous quality improvement within the system.
Incorporate culturally competent care as core value of Canada’s cancer control strategy	It embodies diversity, the need for professional skills development and system changes and requires an integrated and sustainable approach. Availability of interpreters is an essential component of culturally competent and safe service delivery systems.
Action strategies to address systemic barriers to culturally competent care	Envision and build programs with vulnerable persons in mind to create the kinds of systems that will serve everyone.
Collection of demographic, cultural and socioeconomic contextual variables within cancer data to evaluate the effectiveness of our cancer control system to serve the needs of vulnerable populations	The ethical and social sensitivities surrounding identifiers must be addressed.
Action strategies to address inequities in access and use of services across the cancer continuum	Enhance services to rural and remote populations. Explore and develop strategies that address issues of poverty, language, education, culture and other barriers and how this affects access to care.
Engage community partnership as a strategy for success	Consultation with local community organizations is essential to identify their needs and to plan effective cancer control strategies. Network across/with other national agencies or programs such as chronic disease and/or disease specific interventions are equally needed to create coordinated actions/activities, avoid duplication, create synergies and collaborate for improved outreach to underserved populations.

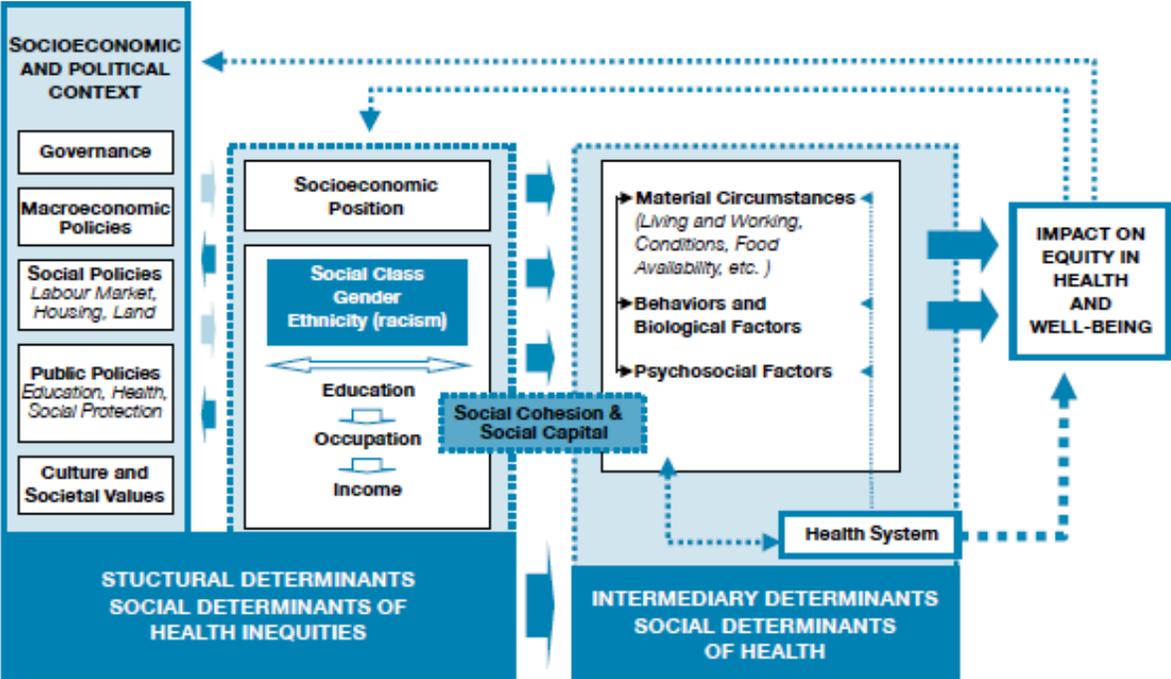
Table 3: Types of Models of Survivorship Care

Model	Description	References (examples)
Oncologist Led	Specialist continues to provide survivorship care in a cancer centre.	Van Harten, Paradiso, & Le Beau, 2013
Primary Care Provider Led (also called Community Based Model)	Survivorship care provided by the primary care provider with referral to specialists as needed	Grunfeld, 1995
Nurse-led	<ol style="list-style-type: none"> 1. Nurse Practitioner or Registered Nurse with oncology expertise leading survivorship clinic based in either primary care or cancer centre. 2. Nurse navigator based in primary or oncology care setting that moves with survivor through care systems/settings 	<p>Cooper, Loeb, & Smith, 2010; Gates & Krishnasamy 2009</p> <p>Fillion, 2011; Fillion et al., 2012; Pratt-Chapman et al., 2011</p>
Shared Care	Combined services are provided by a primary care provider and a cancer centre	Grunfeld & Earle, 2010
Consultative system	Single or multiple visits for assessment, education, follow up.	Landier, 2009
Cancer Survivorship Clinic	Can be located in cancer centre, tertiary care or primary care settings. Can be a consultative clinic with 1-2 visits, or an ongoing follow-up clinic	Ganz & Hahn 2008
Disease/Treatment Site Model	Can be located in cancer centre, tertiary care or primary care settings. Can be a consultative clinic with 1-2 visits, or an ongoing follow-up clinic	Funk et al., 2014; Stent, 2012

Figure 1: Cancer Trajectory: Canadian Partnership Against Cancer
(*Canadian Partnership Against Cancer, 2012*)



Figure 2: Social Determinants of Health and Health Inequities: World Health Organization
(Solar & Irwin, 2010)



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Are you a cancer survivor?

Do you have experiences and recommendations to share to improve cancer survivorship care systems and resources?

We are exploring how cancer survivors access and experience cancer survivorship care systems and resources. Information gathered in this study will be used to provide recommendations to improve survivorship care for Canadians with cancer.

You can enroll in this study if you are:

- 1) 18 years of age or older,
- 2) Diagnosed with cancer as an adult (at least 18 years of age),
- 3) Finished primary cancer treatment,
- 4) Able to speak and read English,
- 5) Living in British Columbia and
- 6) Willing to participate in one or more interviews.



For more information, please contact the study investigator:

Tracy Truant at (604) XXX-XXXX

tracy.truant@nursing.ubc.ca

APPENDIX B: Letter of Invitation: Survivors

THE UNIVERSITY OF BRITISH COLUMBIA



School of Nursing
T201-2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5

LETTER OF INVITATION - Survivors

Tel: (604) 822-7417
Fax: (604) 822-7466

STUDY: Exploring High Quality Cancer Survivorship Care

Principal Investigator: Dr. Sally Thorne

Co-Investigators: Ms. Tracy Truant, Dr. Colleen Varcoe and Dr. Carolyn Gotay

[Date]

Dear Sir/Madam,

You are invited to participate in a study to better understand how cancer survivors access and experience cancer survivorship care systems and resources. Information gathered through interviews with cancer survivors will be used to provide recommendations and insights to improve survivorship care for Canadians with cancer.

If you agree to participate you will be asked to complete 1-2 one-to-one interviews with a doctoral student researcher in person or by phone. The interview will take 30-60 minutes. I have enclosed a copy of the consent form that contains more information about the study. You may contact Tracy Truant (604-XXX-XXXX) or her doctoral supervisor, Dr. Sally Thorne (604-822-7482), if you would like to discuss the study or if you have questions.

Your participation is voluntary. Whether or not you chose to participate will have no effect on your current or future treatment and care. If you are interested in participating please respond to this email to set up an interview with the doctoral student researcher, Tracy Truant, on a date and time that is convenient to you.

You do not have to respond if you are not interested in this study. You will receive one follow-up email that you may ignore if you do not wish to participate.

Sincerely,

A handwritten signature in black ink, appearing to read 'Tracy Truant', with a horizontal line extending to the right.

Tracy Truant, RN, MSN, PhD(c)
Doctoral Candidate, UBC School of Nursing

APPENDIX C: Interview Guide: Survivors

Interview Guide: Survivors

Proposed study end in view: Insights and recommendations regarding the design of a quality (equitable) system of care for cancer survivors, which addresses survivors' needs both at an individual and aggregate level.

Introduction:

I am interested in better understanding how cancer systems of care and resources can best meet cancer survivors' needs. Your perspective will help me to understand the kinds of services and resources that have been helpful, and where you see improvements can be made. Also, your perspective on how decision makers should support the development of a high quality, equitable cancer survivorship care system will provide valuable insights and direction.

- I use the term “cancer survivor” in relation to this study. Is that a term you would use to refer to yourself? Why or why not?
 - What are some of the challenging aspects of cancer survivorship?
 - What are some of the positive aspects?
 - What do you think others might say about you as a cancer survivor?

- Tell me about your experience of finishing cancer treatment and returning back “to your old life”.
 - What have been some of the positive experiences? What has been hard or challenging about that experience?
 - How has your health been since finishing treatment?
 - What have you been doing to help your health?
 - Probe diet, exercise, lifestyle changes, CAM, etc.
 - Probe factors influencing ability to practice health management strategies
 - Where have you gone to get help/support for your health after treatment?
 - What do you worry the most about regarding your future and your health?
 - How similar/different do you think your experience has been in relation to other survivors?

- What has been your experience of accessing (health) care after finishing primary treatment?

- How do you think your experience of accessing health care after cancer treatment is similar/different than “others like you”?

- In what capacity did your health care providers assist you to make the transition from treatment to “after treatment”?

- Looking back on your cancer diagnosis and treatment, what do you think health care providers or others around you could do to prepare you for the transition after finishing cancer treatment?
- Probe treatment decision making, beginning conversations about life after treatment early in the treatment trajectory, etc.
- Canadians should have equal access to high quality care according to the Canada Health Act, yet we have fiscal realities to deal with that require us to think carefully about how to design system of care. What recommendations do you have for decision makers to support the development of a high quality, equitable cancer survivorship care system?
 - How would you design a system of care that meets your own needs?
 - Probe tensions between meeting individual needs and population/aggregate needs
 - What role ought primary care providers (physicians, nurses) play in cancer survivorship care?
 - What role ought survivors play in managing their survivorship needs?
- Who should be informed of the findings of this study to influence the development of equitable high quality cancer survivorship care? What strategies do you recommend for sharing these findings to foster optimal uptake?
- Is there anything else you would like to tell me about your experience or thoughts about cancer survivorship care?

APPENDIX D: Informed Consent: Survivors

THE UNIVERSITY OF BRITISH COLUMBIA



School of Nursing
T201-2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

CONSENT FORM: Survivors

STUDY: Exploring High Quality Cancer Survivorship Care

STUDY TEAM:

Principal Investigator:

Dr. Sally Thorne, PhD, RN, DSc (Hon), FAAN, FCAHS 604-822-7482
Professor, UBC School of Nursing
Doctoral Supervisor for Ms. Tracy Truant

Co-Investigators:

Ms. Tracy Truant, RN, MSN, PhD(c) 604-XXX-XXXX
Doctoral Candidate, UBC School of Nursing
Dr. Colleen Varcoe, PhD, RN 604-827-3121
Professor, UBC School of Nursing
Dr. Carolyn Gotay, PhD, FCAHS 604-827-4022
Professor, UBC School of Population and Public Health

Sponsor: This study is funded by a Canadian Institutes of Health Research (CIHR) Frederick Banting and Charles Best Canada Graduate Scholarships Doctoral Award.

1. INVITATION

You are being invited to take part in this research study because you have completed treatment for your cancer. We are interested in your perspectives and experiences within the cancer survivorship system of care as well as any recommendations you may have to improve cancer survivorship care for Canadians.

2. YOUR PARTICIPATION IS VOLUNTARY

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences to the medical care you receive.

Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to participate in this study, you will be asked to sign this consent form.

Please take time to read the following information carefully and to discuss it with individuals important to you before you decide.

3. WHO IS CONDUCTING THE STUDY?

The study is being conducted by a Doctoral Candidate from UBC School of Nursing and Faculty from UBC School of Nursing and School of Population and Public Health. This study is a graduate dissertation toward requirements for a Doctor of Philosophy (PhD) degree for Ms. Truant. Funding for this study is coming from a Canadian Institutes of Health Research (CIHR) Frederick Banting and Charles Best Canada Graduate Scholarships Doctoral Award.

There are no conflicts of interest to report for any of the researchers on this study.

4. WHAT IS THE PURPOSE OF THE STUDY?

This research project aims to understand how cancer survivors access and experience cancer survivorship care systems and resources. Information gathered through interviews with cancer survivors will be used to provide recommendations and insights to improve survivorship care for Canadians with cancer.

5. WHO CAN PARTICIPATE IN THIS STUDY?

You are invited to participate in this study if you are/have:

- 18 years of age or older,
- Diagnosed with cancer as an adult (at least 18 years of age),
- Finished primary cancer treatment (e.g. chemotherapy, radiation, surgery),
- Able to speak and read English,
- Living in British Columbia and
- Willing to participate in one or more interviews.

6. WHO SHOULD NOT PARTICIPATE IN THE STUDY?

You cannot participate in this study if:

- You were diagnosed with cancer as a child (<18 years)
- You have been diagnosed with non-melanoma skin cancer (e.g. Basal cell cancer)

7. WHAT DOES THE STUDY INVOLVE?

If you agree to take part in this study, you will be asked to complete 1-2 one-on-one interviews with the doctoral student researcher. The interviews can be conducted by telephone or in-person at a date and time convenient to you. The interviews will be digitally recorded. During the interview you will be asked about your experiences of finishing cancer treatment and accessing and receiving survivorship care. Topics such as health promotion activities and experiences of receiving care after cancer treatment in the primary care system will also be covered. Your opinions and recommendations will also be sought on how to improve cancer survivorship care systems and resources so that all Canadians have access to high quality survivorship care. You will be asked to provide brief demographic and disease information in a short written survey. The interviews will last 30-60 minutes. You are free to stop the interview or chose not to answer any questions at any time.

8. STUDY RESULTS

The results of this study will be reported in a doctoral dissertation and also may be published in journal articles and books. Findings may also be summarized for use by policy makers and used for teaching purposes.

If desired, you may receive an executive summary of the study results by choosing the option on this consent form to have this summary sent to you.

9. WHAT ARE THE POSSIBLE HARMS AND DISCOMFORTS?

There are no anticipated risks to participating in this research study. Potential risks may include recalling past stressful events related to cancer diagnosis, treatment and care. Referral to health professionals to assist in coping with past stressful events will be offered in these circumstances.

10. WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING?

There are no direct benefits to you from taking part in this study. This study will provide you with an opportunity to share your perspectives on how to improve the cancer care system for cancer survivors. We hope that the information learned from this study can be used in the future to benefit Canadian cancer survivors.

11. WHAT HAPPENS IF I DECIDE TO WITHDRAW MY CONSENT TO PARTICIPATE?

You may withdraw from this study at any time without giving a reason. You may also decide to request your data be withdrawn from the study at any times without giving a reason.

12. WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Your confidentiality will be respected. However, research records identifying you may be inspected in the presence of the Investigator or her designate by representatives of UBC Research Ethics Boards for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent.

The information collected in this study may be used for teaching purposes without revealing any information that would identify you or the persons you may discuss within the interview(s). The information we get from this study might be used again for more research on cancer survivorship, but only if approved by the appropriate university committees.

You will be assigned a unique study number as a participant in this study. Only this number will be used on any research-related information collected about you during the course of this study, so that your identity [i.e., your name or any other information that could identify you] as a participant in this study will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request.

Disclosure of Race/Ethnicity

Studies involving humans now routinely collect information on race and ethnic origin as well as other characteristics of individuals. Providing information on your race or ethnic origin is voluntary.

Disclose of Income/Employment

Studies involving humans that want to understand health-care utilization and financial burden of an intervention or health condition collect information on income and employment to undertake a cost-analysis. Providing information on your income and employment is voluntary.

13. WHAT WILL THE STUDY COST ME?

You will not incur any costs by participating in this study. You will be given the option of completing a telephone or in-person interview.

You will not be paid for participating in this study. Parking will be reimbursed for in-person interviews.

14. WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?

If you have any questions or desire further information about this study before or during participation, you can contact Ms. Tracy Truant (604-XXX-XXXX) or her Doctoral Supervisor, Dr. Sally Thorne (604-822-7482).

15. WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A SUBJECT?

If you have any concerns or complaints about your rights as a research subject and/or your experiences while participating in this study, contact the Research Subject Information Line in the University of British Columbia Office of Research Services by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).

16. SUBJECT CONSENT TO PARTICIPATE

Study: Exploring High Quality Cancer Survivorship Care

Subject Consent

My signature on this consent form means:

- I have read and understood the subject information and consent form.
- I have had sufficient time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had satisfactory responses to my questions.

- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time without changing in any way the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to *me*

I will receive a signed copy of this consent form for my own records.

I consent to participate in this study.

Subject's Signature Printed name Date

Signature of Printed name Study Role / Date
Person Obtaining Consent

I would like to receive an Executive Summary of the study findings when available. Please forward these study findings to me via:

Email:
 YES NO Initials _____

Email address: _____

Surface Mail:
 YES NO Initials _____

Postal address: _____

APPENDIX E: Demographic Form: Survivors

Demographic Information: Survivors

Study Identification Number: _____

1. Age (<25, 25-40, 41-50, 51-60, 61-70, 71-80, >80)
2. Gender (M, F, transgendered, two spirited)
3. Highest education (high school or less, trade or vocational, post secondary and post graduate)
4. Current employment status (retired, paid work full or part time, not paid work – e.g. homemaker, cannot work due to illness, unemployed, other)
5. Marital Status (married, common-law, separated, divorced, single)
6. (Household) Income (<25,000, 26-50,000, 51-80,000, >80,000)
7. Postal code
8. Cancer diagnosis and date (e.g. tumor site and year)
9. Cancer treatment received in last month (none, hormone/antibody treatment, chemotherapy, radiation therapy, surgery, bone marrow/stem cell transplant, complementary/alternative treatment)
10. Current cancer status (Active treatment, having follow up, follow up has ended, cancer returned or spread, palliative care)
11. Concurrent medical conditions (e.g. diabetes, heart disease, arthritis)
12. Who primarily manages your care since completing your cancer treatment? (e.g. Family doctor, oncologist, nurse practitioner, other)
13. Use of resources outside of the conventional cancer treatment/survivorship care system (e.g. naturopath, massage, etc.)
14. Health promotion practices (e.g. exercise, diet,)

APPENDIX F: Recruitment Email: Stakeholders

[Date]

Dear *(Name)*,

As a health professional with significant experience in cancer survivorship care, you are invited to participate in a study to explore how various factors influence the development of and access to high quality survivorship care for Canadians with cancer.

The study involves 1-2 telephone or in-person interviews lasting 30-45 minutes.

Information gathered through these interviews will be used to provide recommendations and insights to improve high quality survivorship care models and resources for Canadians with cancer.

Please see the attached Letter of Information and Consent Form for more detailed information about the study.

To participate or ask questions, please contact Tracy Truant (tracy.truant@nursing.ubc.ca or 604-XXX-XXXX).

APPENDIX G: Letter of Invitation: Stakeholders

THE UNIVERSITY OF BRITISH COLUMBIA



School of Nursing
T201-2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5

LETTER OF INVITATION - Stakeholders

Tel: (604) 822-7417
Fax: (604) 822-7466

STUDY: Exploring High Quality Cancer Survivorship Care

Principal Investigator: Dr. Sally Thorne

Co-Investigators: Ms. Tracy Truant, Dr. Colleen Varcoe and Dr. Carolyn Gotay

[Date]

Dear *[name]*,

You are being invited to participate in this study because you have experiences and insights into cancer survivorship care systems and models of care in Canada. We are interested in your perspectives and experiences within the cancer survivorship system of care as well as any recommendations you may have to improve cancer survivorship care for Canadians. Information gathered through interviews with survivors and stakeholders will be used to provide recommendations and insights to improve survivorship care for Canadians with cancer.

If you agree to participate you will be asked to complete 1-2 one-to-one interviews with a doctoral student researcher in person or by phone. The interview will take 30-45 minutes. I have enclosed a copy of the consent form that contains more information about the study. You may contact Tracy Truant (604-XXX-XXXX) or her doctoral supervisor, Dr. Sally Thorne (604-822-7482), if you would like to discuss the study or if you have questions.

Your participation is voluntary. Whether or not you chose to participate will have no effect on your current or future treatment and care. If you are interested in participating please respond to this email to set up an interview with the doctoral student researcher, Tracy Truant, on a date and time that is convenient to you.

You do not have to respond if you are not interested in this study. You will receive one follow-up email that you may ignore if you do not wish to participate.

Sincerely,

A handwritten signature in black ink, appearing to read 'Tracy Truant', written over a light grey rectangular background.

Tracy Truant, RN, MSN, PhD(c)
Doctoral Candidate, UBC School of Nursing

APPENDIX H: Informed Consent: Stakeholders

THE UNIVERSITY OF BRITISH COLUMBIA



CONSENT FORM: Stakeholders

School of Nursing
T201-2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

STUDY: Exploring High Quality Cancer Survivorship Care

STUDY TEAM:

Principal Investigator:

Dr. Sally Thorne, PhD, RN, DSc (Hon), FAAN, FCAHS 604-822-7482
Professor, UBC School of Nursing
Doctoral Supervisor for Ms. Tracy Truant

Co-Investigators:

Ms. Tracy Truant, RN, MSN, PhD(c) 604-XXX-XXXX
Doctoral Candidate, UBC School of Nursing
Dr. Colleen Varcoe, PhD, RN 604-827-3121
Professor, UBC School of Nursing
Dr. Carolyn Gotay, PhD, FCAHS 604-827-4022
Professor, UBC School of Population and Public Health

Sponsor: This study is funded by a Canadian Institutes of Health Research (CIHR) Frederick Banting and Charles Best Canada Graduate Scholarships Doctoral Award.

1. INVITATION

You are being invited to participate in this study because you have experiences and insights into cancer survivorship care systems and models of care in Canada. We are interested in your perspectives and experiences within the cancer survivorship system of care as well as any recommendations you may have to improve cancer survivorship care for Canadians. Information gathered through interviews with cancer survivorship system stakeholders will be used to provide recommendations and insights to influence the development of and access to high quality survivorship care for Canadians with cancer.

2. YOUR PARTICIPATION IS VOLUNTARY

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences.

Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to participate in this study, you will be asked to sign this consent form.

Please take time to read the following information carefully and to discuss it with individuals important to you before you decide.

3. WHO IS CONDUCTING THE STUDY?

The study is being conducted by a Doctoral Candidate from UBC School of Nursing and Faculty from UBC School of Nursing and School of Population and Public Health. This study is a graduate dissertation toward requirements for a Doctor of Philosophy (PhD) degree for Ms. Truant. Funding for this study is coming from a Canadian Institutes of Health Research (CIHR) Frederick Banting and Charles Best Canada Graduate Scholarships Doctoral Award.

There are no conflicts of interest to report for any of the researchers on this study.

4. BACKGROUND TO THE STUDY

More cancer survivors are living longer as a result of advances in cancer treatment and care. However, many survivors continue to face life-long physical, psychological, sexual, social, and financial challenges after treatment completion, including lingering cancer recurrence and prevention concerns, negatively impacting quality of life. Compounding these challenges, the survivorship system of care can be confusing and complicated to navigate. Not all cancer survivors are able to access high quality cancer survivorship care that optimally meets their needs. A variety of factors, conditions, contexts and structures within the cancer treatment and survivorship care systems may be unwittingly creating barriers for some survivors to achieve equitably high quality cancer survivorship care.

5. WHAT IS THE PURPOSE OF THE STUDY?

As the cancer survivorship system of care is still in its early phases of development, this is an opportune time to include system stakeholder perspectives, insights, reflections and recommendations for enhancements to survivorship system and resources to improve accessibility and better alignment with survivors' needs. This study provides an opportunity for cancer survivorship system stakeholder perspectives to inform our understanding of what is needed to ensure both high quality and equity in cancer survivorship care systems in Canada.

Information gathered through interviews with cancer survivors and system stakeholders will be used to provide recommendations and insights to influence the development of and access to high quality survivorship care for Canadians with cancer.

5. WHO CAN PARTICIPATE IN THIS STUDY?

You are invited to participate in this study if you have broad experience and expertise in Canadian cancer survivorship care system(s) or models of care, including insights into the factors, conditions, contexts, and structures that have shaped/have the potential to shape current and future survivorship care. You may be living/working in any province in Canada and are willing to participate in one or more interviews.

6. WHO SHOULD NOT PARTICIPATE IN THE STUDY?

You cannot participate in this study if your experience with survivorship systems of care is *primarily* based in the United States or other country.

7. WHAT DOES THE STUDY INVOLVE?

If you agree to take part in this study, you will be asked to complete 1-2 one-on-one interviews with the doctoral student researcher. The interviews can be conducted by telephone or in-person at a date and time convenient to you. The interviews will be digitally recorded. During the interview you will be asked about your experiences of developing, leading and/or participating in cancer survivorship systems of care and resources; your perspectives on how various factors may influence development of and/or access to these survivorship care systems and resources; and your recommendations for future development of equitable, high quality cancer survivorship care for all Canadians. You will be asked to provide brief demographic and professional information such as your professional designation, your current role and the survivorship population with whom you work. The interview will last 30-45 minutes. You are free to stop the interview or chose not to answer any questions at any time.

8. STUDY RESULTS

The results of this study will be reported in a doctoral dissertation and also may be published in journal articles and books. Findings may also be summarized for use by policy makers and used for teaching purposes.

If desired, you may receive an executive summary of the study results by choosing the option on this consent form to have this summary sent to you.

9. WHAT ARE THE POSSIBLE HARMS AND DISCOMFORTS?

There are no anticipated risks to participating in this research study.

10. WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING?

There are no direct benefits to you from taking part in this study. This study will provide you with an opportunity to share your perspectives on how to improve the cancer care system for cancer survivors. We hope that the information learned from this study can be used in the future to benefit Canadian cancer survivors.

11. WHAT HAPPENS IF I DECIDE TO WITHDRAW MY CONSENT TO PARTICIPATE?

You may withdraw from this study at any time without giving a reason. You may also decide to request your data be withdrawn from the study at any time without giving a reason.

12. WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Your confidentiality will be respected. However, research records identifying you may be inspected in the presence of the Investigator or her designate by representatives of UBC Research Ethics Boards for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent.

The information collected in this study may be used for teaching purposes without revealing any information that would identify you or the persons you may discuss within the interview(s). The information we get from this study might be used again for more research on cancer survivorship, but only if approved by the appropriate university committees.

You will be assigned a unique study number as a participant in this study. Only this number will be used on any research-related information collected about you during the course of this study, so that your identity [i.e., your name or any other information that could identify you] as a participant in this study will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request.

Disclosure of Race/Ethnicity

Studies involving humans now routinely collect information on race and ethnic origin as well as other characteristics of individuals. Providing information on your race or ethnic origin is voluntary.

Disclose of Income/Employment

Studies involving humans that want to understand health-care utilization and financial burden of an intervention or health condition collect information on income and employment to undertake a cost-analysis. Providing information on your income and employment is voluntary.

13. WHAT WILL THE STUDY COST ME?

You will not incur any costs by participating in this study. You will be given the option of completing a telephone or in-person interview. Parking will be reimbursed for in-person interviews.

You will not be paid for participating in this study.

14. WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?

If you have any questions or desire further information about this study before or during participation, you can contact Ms. Tracy Truant (604-XXX-XXXX) or her Doctoral Supervisor, Dr. Sally Thorne (604-822-7482).

15. WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A SUBJECT?

If you have any concerns or complaints about your rights as a research subject and/or your experiences while participating in this study, contact the Research Subject Information Line in the University of British Columbia Office of Research Services by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).

16. SUBJECT CONSENT TO PARTICIPATE

Study: Exploring High Quality Cancer Survivorship Care

Subject Consent

My signature on this consent form means:

- I have read and understood the subject information and consent form.
- I have had sufficient time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time without changing in any way the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to *me*

I will receive a signed copy of this consent form for my own records.

I consent to participate in this study.

Subject's Signature Printed name Date

Signature of Printed name _____ / _____
Person Obtaining Consent Study Role / Date

I would like to receive an Executive Summary of the study findings when available. Please forward these study findings to me via:

Email:
 YES NO Initials _____

Email address: _____

Surface Mail:
 YES NO Initials _____

Postal address: _____

APPENDIX I: Demographic Form: Stakeholders

Study Identification Number: _____

- Age (<25, 25-40, 41-50, 51-60, 61-70, 71-80)
- Gender (M, F, transgendered, two spirited)
- Province
- Educational preparation (high school or less, trade or vocational, post secondary, undergraduate degree, Master's degree, doctoral degree)
- Professional designation (please list) _____
- Length of time in profession (< 5 years, 5-10 years, 11-20 years, 21+ years)
- Title/role (name, and whether local, regional, provincial, national) _____
- Length of time in role _____
- Type of program/model/resource that you are involved in (clinical program, research, advocacy group, support group, education program, program development)
- Where is the program/model/resource located? (Cancer centre, primary care, academic setting, community based, government, other _____)
- Population of survivors that the program/model/resource addresses

- How is this program/model/resource funded? (private, public, mix, other)

APPENDIX J: Interview Guide: Stakeholders

Proposed study end in view: Insights and recommendations regarding the design of an equitable high quality system of care for cancer survivors, which addresses survivors' needs both at an individual and aggregate level.

I am interested in better understanding how cancer systems of care and resources can best meet cancer survivors' needs. Your perspective will help me to understand the kinds of services and resources that have been helpful, and where you see improvements can be made. Also, your perspective on how decision makers should support the development of a high quality, equitable cancer survivorship care system will provide valuable insights and direction.

- Tell me about your experiences of developing the survivorship model of care/program/resource/role in which you are currently are involved.
- What factors were taken into account in the development of these models/programs/resources/roles?
 - Probe historical, political, social, economic, personal and other factors
 - Probe end in view. Is this being met? Why or why not?
 - Were survivors' voices involved? How what this accomplished?
 - Probe barriers and facilitators
 - If you could do this all over from the start again, what would you do differently?
- What does high quality equitable cancer survivorship care in Canada look like to you? What are the key principles, elements or considerations in the development of such? What role ought survivors play in developing these models of care and resources?
- What kinds of things do you think decision makers should consider when developing high quality equitable survivorship models of care and resources?
- How does one balance the individual needs of survivors with those of the population of survivors given our Canada Health Act and need to be fiscally responsible?
- People are complex beings and cannot be essentialized into only one group (e.g. Aboriginal, gender based) and have all of their survivorship needs met. When we organize care and resources based on these groups, we are likely to advantage some and marginalize others. How could we do things differently to get around this challenge?
 - What factors do we need to consider?
 - Who should be involved in sorting through this complex issue?
- What role ought survivors play in managing their survivorship needs?

- Who else would you recommend that I talk to about equitable, high quality survivorship care in Canada?
- Who should be informed of the findings of this study to influence the development of equitable high quality cancer survivorship care? What strategies do you recommend for sharing these findings to foster optimal uptake?
- Is there anything else that you would like to tell me that you feel is important to consider when developing survivorship care in the future?

Appendix K: Documentary Sources of Data

1. Survivorship Guidelines:

Person-Centred Care

Biddy, R., Griffin, C., Johnson, N., Larocque, G., Messersmith, H., Moody, L., ...Singh, S. (2015). *Person-centred care guideline*. Toronto, Canada: Cancer Care Ontario.

Psychosocial/Supportive Care

Denlinger, C.S., Ligibel, J.A., Are, M., Baker, K.S., Broderick, G., Denmark-Wahnefried, W. et al. ...Zee, P. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) Survivorship Version 2.2016. © 2016 National Comprehensive Cancer Network, Inc. NCCN.org.

Howell, D., Currie, S., Mayo, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Simpson, J., Collacutt, V., McLeod, D., and Digout, C. (2009). *A pan-Canadian clinical practice guideline: Assessment of psychosocial health care needs of the adult cancer patient*. Toronto, Canada: Canadian Partnership Against Cancer.

Howell, D., Hack, T.F., Oliver, T.K., Chulak, T., Mayo, S., Aubin, M., Chasen, M., Earle, C.C., Friedman, A.J., Green, E., Jones, G.W., Jones, J.M., Parkinson, M., Payeur, N., Sabiston, C.M., Sinclair, S., Tompson, M. (2011). *A Pan-Canadian Practice Guideline: Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors*. Toronto, Canada: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology.

Cancer Journey Action Group (2009). Guide for implementing screening for distress, the 6th vital sign. Canadian Partnership Against Cancer

Breast

B.C. Cancer Agency. Cancer Management Guidelines, Breast: Survivorship care B C Cancer Agency, 2016

Cancer Care Ontario. Ontario's Position on Guidelines for Breast Cancer Well Follow-Up Care. Cancer Care Ontario, 2013

Harris, S.R., Schmitz, K.H., Campbell, K.L. & McNeely, M.L. Clinical practice guidelines for breast cancer rehabilitation: Syntheses of guideline recommendations and qualitative appraisals. *Cancer*, 2012; 118 (8 Suppl): 2312– 24.

Khatcheressian, J.L., Hurley, P., Bantug, E., Esserman, L.J., Grunfeld, E. Halberg, F., et al....Davidson, N. (2013). Breast cancer follow-up and management after primary

treatment: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol.* 31, 961-965.

Runowicz, C. D., Leach, C. R., Henry, N. L., Henry, K. S., Mackey, H. T., Cowens-Alvarado, R. L., . . . Ganz, P. A. (2016). American Cancer Society/American Society of Clinical Oncology breast cancer survivorship care guideline: ACS/ASCO breast cancer survivorship guideline. *CA: A Cancer Journal for Clinicians*, 66(1), 43-73. doi:10.3322/caac.21319

Prostate

Skolarus, T.A., Wolf, A.M., Erb, N.L., et al...Cowens-Alvarado, R.L. (2014). American Cancer Society prostate cancer survivorship care guidelines. *CA Cancer J Clin*, 64, 225-249.

Resnick, M. J., Lacchetti, C., Bergman, J... Penson, D.F (2015). *Journal of clinical oncology: Prostate cancer survivorship care guideline: American society of clinical oncology clinical practice guideline endorsement*. Alexandria, VA: American Society of Clinical Oncology. doi:10.1200/JCO.2014.60.2557

Matthew A, Souter LH, Breau RH, Canil C, Haider M, Jamnicky R, et al. Follow-up care and psychosocial needs of survivors of prostate cancer. Toronto (ON): Cancer Care Ontario; 2015 June 16. Program in Evidence-based Care Guideline No.: 26-4.

Colorectal

El-Shami, K., Oeffinger, K. C., Erb, N. L., Willis, A., Bretsch, J. K., Pratt-Chapman, M. L., . . . Cowens-Alvarado, R. L. (2015). American cancer society colorectal cancer survivorship care guidelines. *CA: A Cancer Journal for Clinicians*, 65(6), 427-455. doi:10.3322/caac.21286

Members of the Colorectal Cancer Survivorship Group. Follow-up care, surveillance protocol, and secondary prevention measures for survivors of colorectal cancer. Toronto (ON): Cancer Care Ontario; 2016 Mar 15. Program in Evidence-based Care Evidence-Based Series No.: 26-2 Version 2.

Head and Neck

Cohen, E. E. W., LaMonte, S. J., Erb, N. L., Beckman, K. L., Sadeghi, N., Hutcheson, K. A., . . . Pratt-Chapman, M. L. (2016). American cancer society head and neck cancer survivorship care guideline: ACS HNC survivorship care guideline. *CA: A Cancer Journal for Clinicians*, 66(3), 203-239. doi:10.3322/caac.21343

Lymphoma

Sussman, J., Souter, L.H., Grunfeld, E., Howell, D., Gage, D., Keller-Olaman, S. & Brouwers. M. (2012). *Models of care for cancer survivorship*. Program in Evidence-based Care Evidence-Based Series, No.: 26-1). Toronto, Canada: Cancer Care Ontario.

Lung

Ung, Y.C., Souter, L.H., Darling, G., Dobranowski, J., Donohue, L., Leighl, N., Ellis, P.M. and the Lung Cancer Follow-up Expert Panel. Follow-up and Surveillance of Curatively Treated Lung Cancer Patients. 2014. Program in Evidence-Based Care Evidence-Based Series No.: 26-3.

Models of Care/Organization of Survivorship Services

Howell, D., Hack, T.F., Oliver, T.K., Chulak, T., Mayo, S., Aubin, M., Chasen, M., Earle, C.C., Friedman, A.J., Green, E., Jones, G.W., Jones, J.M., Parkinson, M., Payeur, N., Sabiston, C.M., Sinclair, S., Tompson, M. (2011). A Pan-Canadian Practice Guideline: Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors. Toronto, Canada: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology.

Sussman, J., Souter, L.H., Grunfeld, E., Howell, D., Gage, D., Keller-Olaman, S., & Brouwers. M. (2012) *Models of Care for Cancer Survivorship*. Toronto, ON. Cancer Care Ontario. Program in Evidence-based Care Evidence-Based Series, No.: 26-

Cancer Journey Portfolio. (2012). *Navigation: A Guide to Implementing Best Practices in Person-Centred Care*. Toronto, ON: Canadian Partnership Against Cancer. www.cancerview.ca.

Health Promotion

Kushi LH, Doyle C, McCullough M et al. American Cancer Society Guidelines on nutrition and physical activity for cancer prevention: reducing the risk of cancer with healthy food choices and physical activity. *CA Cancer J Clin* 2012; 62: 30–67.

Rock, C.L., Doyle, C., Demark-Wahnefried, W, et al. Nutrition and physical activity guidelines for cancer survivors. *CA Cancer J Clin* 2012; 62: 243–74

Symptom Management Guidelines

Cancer Care Ontario. Symptom management guidelines. Toronto, Canada: Cancer Care Ontario

BC Cancer Agency. Symptom management guidelines. Vancouver, Canada: BC Cancer Agency

Stacey, D. for the Pan-Canadian Oncology Symptom Triage and Remote Support (COSTaRS) team (2016). Remote symptom practice guides for adults on cancer treatments. Ottawa, Canada: University of Ottawa School of Nursing and the Ottawa Hospital Research Institute.

2. Survivorship Care Plans

- a. American Society of Clinical Oncology (ASCO) Survivorship Treatment and Care Plans
- b. LIVESTRONG care plans
- c. Journey Forward survivorship care plans and resources

3. Policies/Position Statements/Frameworks

- a. Cancer Care Ontario (CCO) Position statement on guidelines for breast cancer well follow up care
- b. Canadian Partnership Against Cancer (CPAC)
 - i. Getting quality care as a cancer patient: What you can expect; what you can do (2008) {
 - ii. Our vision for cancer care (2010)
- c. British Columbia Ministry of Health
 - i. British Columbia Ministry of Health (2014). Setting priorities for the BC health system.
 - ii. British Columbia Ministry of Health (2015). The British Columbia patient-centred care framework. BC Ministry of Health.
 - iii. Lake, T., (2015). Delivering a patient-centred high performing and sustainable health system in BC: A call to build consensus and take action. BC Ministry of Health.
 - iv. British Columbia Ministry of Health (2015). Primary and community care in BC: A strategic policy framework.
- d. Fitch, M., Porter, H., & Page, B. (Eds) (2008). Supportive care framework: A foundation for person-centred care.

4. Survivor support, education and information programs/resources

- a. Electronic Living Laboratory in Cancer Survivorship Research (ELLICSR)
- b. British Columbia Cancer Agency Survivorship Program (Strategic Plan 2012-2015)
- c. The Ottawa Hospital Wellness beyond Cancer Program
- d. Ottawa Integrative Cancer Centre
- e. Cancer Transitions ©
- f. Cancer Chat Canada at the de Souza Institute
- g. CancerBridges
- h. Callanish
- i. Be Active
- j. Cancer and Work website
- k. Canadian Partnership Against Cancer (CPAC) CancerView website
- l. Canadian Cancer Society website: Life after Cancer Treatment
- m. Young Adult Cancer Canada website

5. Organizations and Initiatives

- a. Family Practice Oncology Network, BC Cancer Agency
- b. Canadian Partnership Against Cancer
 - i. Person-centred perspective initiative
 - ii. Person-centred perspective: Survivorship initiative
- c. Canadian Cancer Society (CCS) website – survivorship related documents
- d. Canadian Cancer Survivorship Research Consortium (CCSRC)
- e. Canadian Cancer Society Research Institute (CCSRI)
- f. Canadian Cancer Research Alliance (CCRA)

6. Reports/Discussion Papers/Recommendations

- a. IOM (2006). Hewitt, Greenfield, Stovall (Eds). From cancer patient to cancer survivor: Lost in transition
- b. IOM (2013). Levit et al. Delivering high quality cancer care: Charting a new course for a system in crisis.
- c. CPAC: The future of cancer control in Canada. A discussion paper on the cancer control priorities for 2012-2017.
- d. CPAC: We see progress: The Canadian strategy for cancer control 2017-2022
- e. CPAC: The 2016 cancer system performance report
- f. CPAC: Environmental scan of cancer survivorship in Canada: Conceptualization, practice and research.
- g. CPAC: Canadian invitational cancer survivorship workshop: Creating an agenda for cancer survivorship (2008)
- h. CPAC: The Canadian Strategy for Cancer Control: A Cancer Plan for Canada (2006)
- i. CPAC: Cancer Care for all Canadians: Improving access and minimizing disparities for underserved populations – Part 1 of 2 (2008)
- j. CPAC/BCCA – Fostering Cancer Survivorship Research in Canada – Proceedings from National Consortium (2010)
- k. Cancer Survivorship: creating uniform and comprehensive supportive care programming in Canada (2010)
- l. CPAC/CAPO: Return to work and cancer (2011)
- m. CPAC – Examining disparities in cancer control: A system performance special focus report (2014)
- n. CPAC: Advances in survivorship care: Resources, lessons learned and promising practices (2012).
- o. CPAC: Transitions in Care study – Regional Consultation Sessions (2014)
- p. Canadian Cancer Research Alliance (CCRA) (2013) Investment in cancer survivorship research in Canada, 2005-2010.
- q. Chomik TA. Supporting the Role of Primary Care in Cancer Follow-Up. Canadian Association of Provincial Cancer Agencies, 2010.
- r. Provincial Health Services Authority (2011). Towards Reducing Health Inequities: A Health System Approach to Chronic Disease Prevention. A Discussion Paper. Vancouver, BC: Population & Public Health, Provincial Health Services Authority

7. Toolkits

- a. CPAC (2009) – Promoting equity and diversity in cancer care
- b. CPAC person centered care

APPENDIX L: Survivor and Stakeholder Interview Participants

Survivor Demographics (N=34)

Gender:

Female	26	(76%)
Male	8	(24%)

Age:

24-40 years	3	(9%)
41-50 years	8	(24%)
51-60 years	7	(21%)
61-70 years	12	(35%)
71-80 years	2	(6%)
> 80 years	2	(6%)

Tumour Site:

Breast	15
Haematological	10
Bladder	4
Prostate	4
Cervical	2
Ovarian	2
Other	5

*Note: 7 of the survivors had primary tumours in more than one site

Geographical Location:

Vancouver (8)

Other BC Lower Mainland (8)

*Including: Richmond, New Westminster, Langley, White Rock, Abbotsford, Surrey, Delta, Deep Cove

Vancouver Island (4)

*Including Victoria, Courtney

Southern Interior (7)

*Including New Denver, Penticton, Kamloops, Enderby, Nelson, Rossland

Other (7)

*Including Bowen Island, Whistler, Cortez Island, Prince George

Stakeholder Demographics (N=12)

Professional Designation:

Physicians	6	(50%)
Nurses	6	(50%)

Gender:

Female	11	(92%)
Male	1	(8%)

Location:

BC Cancer (4)

*Including Vancouver Cancer Centre, Fraser Valley Cancer Centre, Prince George Cancer Centre

Other BC

Northern Health (2)

Callanish Society

Other Provinces

Ottawa Hospital Centre

Princess Margaret Hospital, Toronto

Juravinski Cancer Centre, Hamilton

Health Services Alberta

National

Canadian Partnership Against Cancer