ATHABASCA UNIVERSITY

CHILDHOOD CANCER SURVIVORSHIP: A QUALITATIVE DESCRIPTION OF PARENTAL EXPERIENCES WITH SURVIVORSHIP CARE PLANS

BY

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A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF NURSING

FACULTY OF HEALTH DISCIPLINES
CENTRE FOR NURSING AND HEALTH STUDIES

ATHABASCA UNIVERSITY
APRIL, 2015

Athabasca University
FACULTY OF GRADUATE STUDIES

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"Childhood Cancer Survivorship: A Qualitative Description of Parental Experiences with Survivorship Care Plans"

Submitted by

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In partial fulfillment of the requirements for the degree of

Master of Nursing

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Dedication

For David, Chase, and Presley

You'll be on your way up!
You'll be seeing great sights!
You'll join the high fliers
Who soar to high heights!

You're off to great places!
Today is your day!
Your mountain is waiting,
so get on your way!
- *Dr. Seuss*

Thank you for always supporting me in this journey
and in my head-strong determination to climb my own mountain!

Acknowledgements

The success of this thesis would not have been possible without the support of so many people along the way. In particular, my supervisor, Dr. Beth Perry, for always responding to my multitude of questions and for guiding me through all of the struggles and frustrations along the way. Your leadership style is one I admire, with your positivity and encouragement ever engaging to a graduate student. I would also like to thank my committee members, Dr. Caroline Park and Shirley Perry. Your keen interest in my study and willingness to encourage and participate was invaluable to me and my learning. I must also thank all of my friends, family and colleagues for their endless support. Without all of their patience and understanding, I would not have been able to reach this leg of my journey. Finally, a special thank you to my husband, David, for his loving support and seemingly endless patience through all of the ups and downs, and allowing me to accomplish this goal in my personal and professional life.

Abstract

Advancements to treatment and supportive care strategies for childhood cancer have resulted in a shift to managing late effects in the latter stages of the cancer trajectory. Survivorship care plans are communication tools produced by healthcare providers to facilitate and foster an informed and coordinated model of healthcare delivery for survivors and their families. This qualitative descriptive study explored the experiences parents of childhood cancer survivors have had with survivorship care plans. The experiences of eight parents through semi-structured interviews were combined with scholarly elements to expand on the current knowledge of survivorship care in pediatric oncology. Through the iterative process of qualitative content analysis three major themes were identified, Survivorship Care Plan an Important Source of Information, Reliance on Staff, and Varying Emotions of Cancer Survivorship. These results offer a unique perspective of childhood cancer survivorship. Implications for survivorship care and recommendations for future research are discussed.

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Chapter I

Introduction

Increases in survival rates for children with pediatric cancers have escalated in recent years due to advancements in technology and available treatments (Eshelman-Kent, Gilger, & Gallagher, 2009; Freyer, 2010). Despite these advancements, survivors of childhood cancers will potentially experience late effects related to the cancer or to cancer treatment that require specialized follow-up care (Children's Oncology Group, 2007). The parents’ experiences with survivorship care plans (SCP) provided to parents to assist in the management of these late effects experienced by their children are the focus of this study. SCPs are defined and explored further in the ensuing literature review.

Statement of the Problem

With the current large number of cancer survivors, a number that is expected to continue to increase with advances in cancer therapies and an aging population, the Institute of Medicine published a comprehensive report in 2005 to focus efforts on the quality of care that cancer survivors and families receive (Salz, Oeffinger, McCabe, Layne, & Bach, 2012). Within the report are a number of recommendations to alleviate the challenges of survivorship care. One of the top ten recommendations is the creation and implementation of a SCP to facilitate communication and coordination of services, as well as to offer education, resource information, and a comprehensive follow-up plan (Palmer, Jacobs, DeMichele, Risendal, Jones, & Stricker, 2014).

Despite these recommendations by the Institute of Medicine, research conducted over the past decade has shown that there remain significant challenges to implementation of SCPs (Stricker et al., 2011). There is a tremendous amount of support for the use of SCPs from all stakeholders, yet many challenges have been identified, including provision and format of the plan, clinical effectiveness, transferability of the SCP to different survivor groups, and human and financial resources required to effectively develop and use the SCP (Lichtenfeld, 2009; Stricker et al., 2011).

Childhood cancer survivors are one population that have a growing survivorship rate. Because of increased numbers of survivors and length of survivorship this population also has increasing risks of developing late effects (Henderson, Friedman, & Meadows, 2010). The Children's Oncology (COG), the world's largest childhood cancer research group, recognize the need to provide high quality survivorship care to this population and implemented *The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* (COG-LTFU Guidelines) (COG, 2008). Given the extensive nature of the COG-LTFU Guidelines, as well as other identified barriers, coordination of care remains a challenge even in this population (Ganz, Casillas, & Hahn 2008). Many factors are part of developing effective, quality survivorship care. These influencing factors may vary from institution to institution, and from survivor to survivor.

Furthermore, to date research has been limited regarding the perspective of stakeholders who use SCPs and are engaged in survivorship care (Firth, Davies, & Skinner, 2013). Understanding the various experiences and perspectives of survivorship care service users can offer a starting point for improving the quality of care provided to childhood cancer survivors and their families. A variety of situations and factors can impact care, with many survivors not receiving the level of care required to achieve a higher quality of life and successful health outcomes (Kirchoff et al., 2014). The study undertaken for this thesis offers a foundation for understanding the needs of childhood cancer survivors and their families in relation to SCPs.

Research Purpose and Question

The purpose of this study is to explore the experiences parents have had with SCPs in managing the care of their child who has survived cancer. The study focuses on the perspectives of these parents as they have utilized SCP tools provided by the healthcare team to help them maximize the health outcomes and quality of life for their child. The research question is: *What experiences have parents of children who have survived cancer had with SCPs?* Participants were asked to share their experiences in an effort to describe and understand these SCP tools and their contribution to positive health outcomes and quality of life for survivors of childhood cancers.

A description of experiences with SCPs from the perspective of the parent will expand the knowledge and understanding of the role of care plans in the cancer journey, with a focus on the survivorship phase. This study is important because it explores and enhances understanding of parents' experiences with SCPs, including an understanding of the barriers and facilitators for using this tool in the management of survivorship care. While the use of SCPs is recommended there is little research to understand if and how parents use this tool. Descriptions gained from this study have resulted in recommendations regarding content to be included in the SCP, timeliness and format for delivery of the SCP to parents, and barriers and promoters for use of the SCP.

Chapter II

Literature Review

This review of the literature contains an overview of survivorship care in pediatric oncology and endeavors to meet the needs of this ever-growing population. The overview of survivorship examines advancements made in the treatment of childhood cancer, with a focus on long-term consequences of the disease and corresponding treatments. Exploration of survivorship care plans (SCP) as communication tools among care providers to facilitate transfer of information is at the forefront of the review. Furthermore, recommendations from the literature related to SCPs are briefly discussed. Literature related to the current and potential future state of pediatric cancer survivorship care is reviewed.

A systematic literature review was completed using databases in the Athabasca University Library. Academic databases utilized in conducting this literature review included PubMed, CINAHL, CancerLit, SpringerLink, MEDLINE, and Proquest Nursing. Search terms used included “childhood cancer,” “survivorship,” “oncology nursing,” “health information technology,” “survivorship care plans” and “survivorship care models.” Relevant full-text articles were selected based upon initial evaluation of the article title and abstract to determine eligibility. Selection criteria included peer-reviewed articles that were current and published within the last five years and centered on cancer survivorship care with a predominant focus on pediatric oncology. A select number of more dated articles were also chosen for relevance to the topic and limited current sources. Additionally, online resources were reviewed from relevant sites, including the Children's Oncology Group, National Cancer Institute, World Health Organization, and the Institute of Medicine.

Pediatric Cancer Survivorship

Survivor defined. With an increase in cancer survival rates comes an increasing debate over what defines a cancer survivor (Bell & Ristovkski-Slijepcevic, 2013). Three distinct phases of cancer survivorship are identified by Bell and Ristovksi-Slijepcevic (2013), based on the concepts developed by Fitzhugh Mullan, as: acute survival, extended survival, and permanent survival. Permanent survival is the focus of this study since the focus is on long-term quality of life and healthcare outcomes. This long-term phase of survivorship is the period “when recurrence seems increasingly unlikely, although the survivor is continuing to deal with the long-term effects of treatment” (Bell & Ristovksi-Slijepcevic, 2013, p. 409). It should be noted that the National Cancer Institute (2012) further defines survivors of cancer as inclusive of anyone diagnosed with cancer, beginning from initial diagnosis and onwards. In addition, the National Cancer Institute includes family members, friends and caregivers in this definition as they are also directly impacted by the cancer diagnosis and survivorship experience (Hewitt, Weiner, & Simone, 2003).

Late effects. Survivorship care for childhood cancer is a relatively new phenomenon as the incidence of childhood cancer continues to increase and mortality decreases (Freyer, 2010). Advancements in childhood cancer treatments and improvements to supportive care strategies have resulted in a healthier and ageing survivor population. With this growing population comes vulnerability to late effects, defined by the Children's Oncology Group (COG, 2008) as health-related problems related to the cancer or cancer treatment that may occur or persist post-treatment. For example, late effects related to pediatric brain tumours may include hypothyroidism, short stature, diabetes insipidus, and obesity (Hocking et al., 2011). Additionally, impairments in attention, academic achievement and psychological functioning have been identified as late effects occurring in pediatric brain tumour survivors (Hocking et al., 2011). Recognizing that cancer is a long-term, chronic disease, that is experienced differently by survivors and their families, is important to childhood cancer survivorship care.

Furthermore, inclusion of the family in the definition of a survivor requires consideration as the impact of a cancer diagnosis and treatment can have a wide range of effects on the entire family (Patterson, Holm, & Gurney, 2004). The overall coping and adjustment of the family can impact family functioning and impact overall quality of life for the survivor and family members (Ljungman, Cernvall, Grönqvist Ljótsson, Ljungman, & von Essen, 2014). Various behaviours of parents of survivors of childhood cancer have been studied and related to post-traumatic stress symptoms (Bruce, Gumley, Isham, Fearon, & Phipps, 2010; Hoekstra-Weebers, Wijnberg-Williams, Jaspers, Kamps, & van de Wiel, 2012; Ljungman et al., 2014). Some of these post-traumatic stress behaviours include anxiety, distress, fear of recurrence, depression, sleep disturbances, fatigue, re-experience of traumatic events, and persistent avoidance of the traumatic events (Bruce et al., 2010; Ljungman et al., 2014). Childhood cancer treatment can have lasting psychological effects on the survivor and family thus they should be included in the long-term treatment and monitoring. Continued surveillance and interventions post treatment are required to identify the late effect consequences that can impact survivor health and quality of life, inclusive of all family members. How the needs of survivors are coordinated and communicated among caregivers is a necessary consideration for early recognition of late effects.

With nearly 70% of childhood cancer survivors experiencing physical, psychological and/or social late effects, survivorship guidelines endorse systematic follow-up medical care (McCarthy, Campo, & Drew, 2013). Risk for late effects are related to a number of contributing factors including: age at diagnosis, type of treatments, dosage of chemotherapy and/or radiation, and any surgery interventions (Bhatia et al., 2009; Hewitt et al., 2003). While late effects are unique to each individual, management of the effects is complicated by the constant evolution of treatment regimes (Hewitt et al., 2003). The experience of variations in late effects among survivors is evident in those who represent different treatment eras (Hewitt et al., 2003). Consequently, survivors will experience late effects that may be unique to the specific foundations of treatment received during that era (Hewitt et al., 2003).

In addition to the risk of developing late effects, research has shown that most survivors of cancer are not fully aware of their risks for possible late effects or the need for appropriate medical follow-up care (Hewitt et al., 2003). Part of the cause of lack of awareness is deficiency in knowledge related to their disease history and treatment regimen. Parents require this knowledge so they are able to communicate it to other care providers. A lack of knowledge about their child's disease history and treatment regimen can potentially compromise their child's and family's health and quality of life (Hewitt et al., 2003). In an effort to maximize health outcomes and quality of life for survivors, communication of the health history and risks of these patients is necessary (Eshelman-Kent et al., 2011). To facilitate transfer of information among healthcare providers and the patient and family the COG, the world's largest children's cancer research partnership, recommends the implementation of a SCP to function as a communication tool for clinicians to understand past treatments and future risks (Eshelman-Kent et al., 2011).

Survivorship Care Plans

A SCP is a personalized document developed by the oncology team that includes individualized medical information related to diagnosis and treatments, possible late effects and recommended ongoing care including surveillance tests, resources and education materials (Salz et al., 2012; Stricker et al., 2011). Managing late effects of cancer treatment can prove to be difficult when survivors seek medical care from health professionals unfamiliar with their case. These appointments often occur between long-term follow-up visits with their regular oncology team. This happens because, in addition to the follow-up care for health risks related to the cancer and its treatment, survivors will require care for routine medical needs. For example, medical attention for common colds or injuries not related to the cancer or its treatments may result in patients seeking care with a general practitioner rather than seeing an oncologist. The SCP can be useful to parents and general practitioners in such situations.

Not only is the risk for developing late effects one that increases over time, but is also magnified by co-morbidities directly related to the natural process of aging (COG, 2007). This reinforces the need for survivors to obtain both preventative and general medical care subsequent to their treatments for cancer (McCabe et al., 2013). The complex needs of this population of survivors require strategies to manage communication of the individual needs to a variety of practitioners to help bridge gaps (McCarthy et al., 2013).

The Institute of Medicine published a report in 2003, *Childhood Cancer Survivorship: Improving Care and Quality of Life*, highlighting the unique healthcare needs of this population and the barriers to providing adequate care (Landier et al., 2004). This report challenged the COG to develop comprehensive guidelines for follow-up care of childhood cancer survivors (Landier et al., 2004). The development of these guidelines is addressed further in this literature review. Additionally, in a 2005 report by the Institute of Medicine, *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommendations were made to include SCPs as tools in managing the specialized needs of cancer survivors (Salz et al., 2012).

Communication tools. The variability in pediatric cancers and treatments poses a barrier in providing continuity of care across the survivorship spectrum. With variable health risks and individualized needs, coordinated care among primary care providers and cancer centers becomes even more challenging (Bhatia et al., 2009; Sabatino et al., 2013). The function of the SCP is viewed by healthcare providers as one that fosters a collaborative effort in caring for the needs of the cancer survivor. Lichtenfeld (2009) relates the significance of a SCP and summarizes it as a resource for patients, caregivers, physicians, and researchers that inevitably allows for patients and their families to be informed about their care. In an effort to standardize the information that is provided to patients in their SCPs, the COG (2008) states that the SCP should consist of recommendations for follow-up tests and screening based on the Children's Oncology Group Long-Term Follow-Up Guidelines (COG-LTFU Guidelines) and a treatment summary.

The Children's Oncology Group Long-Term Follow-Up Guidelines. The COG-LTFU Guidelines were designed to increase understanding of cancer- and treatment-related complications, such as late effects, that can predispose childhood cancer survivors to an increased chance of morbidity and mortality (Bhatia et al., 2009). Late effects can vary widely and include virtually every system in the body, and can include alterations in organ function, growth and development, neurocognitive function, secondary cancers, and an array of psychological effects (Bhatia et al., 2009). In addition to disease- and treatment-related factors are host-related factors that require considerations, such as gender, age at diagnosis, genetic predisposition, socioeconomic status, and health habits (National Cancer Institute, 2014). The COG-LTFU Guidelines offer comprehensive and standardized follow-up recommended care for survivors of childhood cancers. The COG LTFU- Guidelines are "risk-based, exposure-related clinical practice guidelines for screening and management of late effects resulting from therapeutic exposures used during treatment for pediatric malignancies" (Landier et al., 2004, p. 4980). In an attempt to regulate the approach to managing late effects, the COG-LTFU Guidelines are intended to not only minimize associated healthcare costs to survivors but to promote an increased quality of life (COG, 2007; Landier et al., 2004).

Survivors and their families may be faced with a range of emotions after cancer treatment ranging from relief to anxiety to fear to hope (National Cancer Institute, 2013). Supporting survivors and their families so that they can actively participate in their cancer journey offers a sense of security and sense of moving forward (National Cancer Institute, 2012). A study by Ljungman et al. (2014) shares results that indicate the development and sustained psychological stresses parents of childhood cancer are faced with. Coping and post-traumatic stress symptoms of survivors and their parents were explored by Bruce et al. (2010), revealing a considerable portion of this population who report significant long-term psychological impacts. To assist in mitigating poor health outcomes and improving quality of life, treatment summaries and SCPs are tools that enhance communication among those involved directly in care of the survivor.

Treatment summary. In addition to the care plan for survivors, inclusion of a treatment summary is recommended by the COG (2008). The treatment summary is a document that includes diagnosis, treatments received, dates of treatments and surgeries, cumulative chemotherapy and radiation doses, contact information of treating hospital and physicians, blood products received, current medications, number and location of previous central lines, and any major side effects experienced (COG, n.d.). This clinical information provided in the treatment summary and included with the SCP can impact communication among care providers regarding potential needs of the childhood cancer survivor.

Current State of Survivorship Care Plans

Use of SCPs as tools to summarize treatments and to communicate risks for late effects has been implemented by a number of institutions worldwide (COG, n.d.). Yet, despite research that demonstrates the perceived benefits of care plans (Shalom, Hahn, Casillas, & Ganz, 2011; Horowitz, Fordis, Krause, McKellar, & Poplack, 2009), a study by Stricker et al. (2011) indicates that recommendations for use of SCPs are not being met. Salz et al. (2012) report that a consensus regarding the need for SCPs is evident among caregivers yet disagreements arise concerning the content, format and delivery of the SCP. Furthermore, limited research exists that evaluates the content of SCPs related to improved outcomes for survivors (Stricker et al., 2011). This suggests a need to further evaluate the methods to develop and use SCPs, the content of SCPs, and studies to determine how they could be used efficiently and effectively.

Barriers of SCPs. Among the challenges of delivering survivorship care is the knowledge deficits related to disease, treatment, late effects and follow-up care among survivors, parents and family of survivors, and healthcare professionals (COG, 2007). Structured communication tools, including the SCP and treatment summary, can aid in relaying up-to-date information and resources to survivors, families and their healthcare providers. Salz et al. (2012) conducted a review of studies that investigated the perspectives of stakeholders, including survivors, primary care providers and oncology providers, with particular focus on the content and use of SCPs. Despite identified barriers experienced by stakeholders, such as time, limited resources, format of the SCP, and content of the SCP, the use of SCPs had wide support (Salz et al., 2012). Results from recent studies indicate similar findings, concluding that support for the implementation of SCPs is widespread and opportunities exist to examine the care plans and facilitate their adoption (Sabatino et al, 2013; Stricker et al., 2011). With a focus on childhood cancer survivorship, parents are in a primary position to utilize SCPs and to be at the forefront of evaluation and understanding of how these tools impact the care of their child, specifically their quality of life and health outcomes.

Emotional impact of childhood cancer survivorship. As briefly discussed already, childhood cancer has significant psychological impact on all involved throughout the cancer journey. Having a child diagnosed with cancer can elicit psychological stress for parents and a number of studies have begun to focus on parental late effects (Doshi et al., 2014; Hoekstra-Weebers et al., 2012; Ljungman et al., 2014). There are well-documented studies that focus on the medical and psychological needs of the cancer survivor, as evident in the COG-LTFU Guidelines. Yet in recent years a new emergence of interest in psychological late effects for parents surfaced (Ljungman et al., 2014). A thesis study completed by Cernvall (2014) closely reviewed the literature on post-traumatic stress in parents of childhood cancer survivors in an effort to develop self-help interventions delivered via the internet. Findings of post-traumatic stress in parents and survivors of childhood cancer survivors indicates a model of survivorship care that must be inclusive of all family members and include comprehensive measures and interventions for physical and psychological late effects. Ljungman et al. (2014) report that to date no evidence-based psychological treatments exist to support parents experiencing post-traumatic stress symptoms and suggest that such consideration could be beneficial to overall survivorship care.

Future Direction of Survivorship Care

The information and communication needs of childhood cancer survivors are unique and complex and strategies to manage this are important to consider if survivorship care planning is to make advancements. Some of the identified barriers including format and delivery of the SCP, timeliness of distributing the SCP, availability of current information, and accessibility, could potentially be alleviated through the integration of electronic SCPs that aim to facilitate communication and enhance continuity of care (Vickers et al., 2010). A number of web-based survivorship programs and tools have been identified in the literature and are shown to be valuable in the advancement of survivorship care (Blaauwbroek et al., 2012; Freyer, 2010; Haq et al., 2013; Horowitz et al., 2009; Lichtenfeld, 2009; Salz et al., 2012; Stricker et al., 2011; Vickers et al., 2010). In adult cancer care, a number of SCP templates have been developed including LIVESTRONG®, Journey Forward, and Oncolife, as well as a number of individual institutionally designed templates.

Passport for Care® was developed at Texas Children’s Hospital, in collaboration with the COG, as an internet-based tool that offers individualized, accurate and timely health information to both survivors and healthcare providers (Horowitz et al., 2009). Passport for Care® offers interactive, accurate, timely and individualized information that is now available to COG member institutions (Texas Children's Cancer and Hematology Centers, 2014). Web-based tools facilitate two-way communication and ensure portability of medical records. A report published in 2011 suggests use of creative information technology solutions to improve efficiency of SCPs (Stricker et al., 2011). Incorporation of electronic, web-based SCPs into pediatric oncology survivorship care would be an example of this.

Conclusion

Challenges remain in the coordination of care for childhood cancer survivors as needs are complex and long-term health risks are substantial (Ganz et al., 2008). Survivorship care is directed at providing comprehensive and personalized care plans for survivors that aim to facilitate communication and empower patients and their families. SCPs are key components in continuity of care that offer risk-based, long-term follow-up care. Formal attention to survivorship care will address some of the existing inconsistencies and may offer innovative and technological approaches. The implementation of an electronic SCP could facilitate the fluid and evolving needs of the survivor and advance survivorship care. This study of parental experiences with SCPs to maximize health outcomes and quality of life for their children will be guided by a philosophical framework imbued with assumptions to guide the research process.

Chapter III

Philosophical Framework

Philosophical assumptions

Philosophical assumptions are significant to the research process as they assist the researcher in informing choices along the study trajectory (Creswell, 2013). Four philosophical assumptions have been identified in the literature that need consideration when undertaking a qualitative study: ontological, epistemological, axiological and methodological assumptions (Creswell, 2013). Understanding philosophical assumptions within a qualitative descriptive approach allows for researchers to recognize how their own values and beliefs impact the study.

From an ontological standpoint, qualitative description recognizes the nature of reality as characterized through the multiple views of the researcher and participants, with no one reality being more true or real than another (Creswell, 2013). An epistemological assumption keeps the qualitative descriptive researcher as close as possible to the data and utilizes the experiences of participants as evidence (Sandelowski, 2000). Axiological assumptions can be known in a study through researcher reflexivity and openness of how close the researcher is to the phenomenon being studied (Creswell, 2013). Finally, methodological assumptions in qualitative descriptive research are characterized through an inductive process to frame the procedures throughout the research process (Creswell, 2013). It is through philosophical assumptions that paradigmatic and theoretical assumptions unfold.

Paradigmatic assumptions

Nursing is imbued with theories and paradigms to guide practice while generating nursing knowledge. Paradigms are human constructions that reflect individualistic worldviews (Weaver & Olson, 2006) and it is through the use of paradigms that nursing theory is constructed to guide practice. Qualitative research is embedded in an interpretive paradigmatic framework that holds the assumption that there are multiple realities, with an emphasis on subjectivity and the human experience (Bally, 2012). Variations exist within an interpretive framework that can be used among different methodologies. Creswell (2013) identifies a number of categories, including postpositivism, interpretivism, constructivism, feminism, critical theory, and pragmatism. Within the methodology of qualitative description, pragmatism is viewed as the underlying philosophical assumption that is most congruent to inquiry (Neergaard, Olesen, Andersen, & Sondergaard, 2009).

Pragmatism in qualitative description. Pragmatism within an interpretive framework allows the researcher to focus directly on the research problem, rather than the methods (Creswell, 2013). Qualitative description offers an approach that centers on rich understanding of an experience in everyday terms (Sandelowski, 2000). Pragmatism is a naturalistic approach that affords the researcher flexibility in the process of inquiry by drawing on multiple theories, ideas and perspectives (Doane & Varcoe, 2005). By drawing from a naturalistic inquiry, Sandelowski (2000) argues for using techniques least burdened with existing theoretical commitments. Overtones of various theoretical and philosophical assumptions can be evident within qualitative descriptive studies in a complimentary manner. As the researcher begins to formulate a research question, the pragmatic paradigm imbues assumptions that impact decisions that are made.

Overtones of ethnography, grounded theory, phenomenology and other methodologies can be evident within qualitative description (Sandelowski, 2000). These overtones permit the researcher to encourage participants to recognize and interpret a phenomenon based on their self-experience and the impact their experience has on their own lives (Bjork, Wiebe, & Hallstrom, 2005).

In the parental experiences with SCPs, eliciting perceptions grounded in situational, cultural and historical context can impact the study design (Fochtman, 2008). Through the use of a qualitative descriptive approach, researchers can stay close to the data while allowing for phenomenologic overtones to guide experiences without producing phenomenological data (Sandelowski, 2000). In other words, the phenomenology of survivorship care will be embedded in the topic, but focus on the personal experiences of the phenomenon in a purely descriptive manner eludes the need to represent phenomenologic results. These experiences and perceptions can help play a part in deepening the understandings of childhood survivorship care as experienced from those caring for the child, the parent.

Conclusion

Guiding philosophical and paradigmatic assumptions throughout a qualitative descriptive study offer flexibility for the researcher to shape their methods through an inductive, pragmatic approach. Maintaining an openness and reflexive nature to gather rich experiences parents of childhood cancer survivors have had with SCPs allows the researcher to become embedded within the research topic, eliciting a deeper representation of the data.

Chapter IV

Research Design

The design of this research was chosen explicitly to meet to purpose of eliciting parental experiences of SCPs as tools to maximize the health outcomes and quality of life for their child who has survived cancer. This chapter covers several components of the research design including a qualitative descriptive research design, research methodology including participant recruitment and selection, methods of data collection, and an overview of the process for data analysis. Ethical considerations, adhered to throughout the study, are discussed.

Qualitative Research

Qualitative research is a comprehensive approach to addressing questions that aim to understand particular phenomenon of interest. The nature of qualitative inquiry requires a methodological congruence that helps to shape the research design and ensure consistency during the study (Creswell, 2013). Qualitative researchers are challenged with selecting a methodology that is best poised to reflect the purpose of the study in a clear and meaningful manner. There are key characteristics evident in all qualitative research with different emphasis on various aspects of the research process. These characteristics of qualitative inquiry include, but are not limited to: a natural setting, researcher involvement, use of multiple methods for data collection and analysis, inductive and deductive reasoning, participant perspectives, researcher reflexivity, and capturing a holistic account (Creswell, 2013). Choosing a methodology that fits the research question and purpose is fundamental to offer the researcher a lens to abstract the data, process and understand the data, and link results (Richards & Morse, 2013).

While many forms of qualitative methodologies appear common, there are key differences that make each unique. The lens of a particular method will enable underlying philosophical and paradigmatic assumptions to inform the study (Richards & Morse, 2013). Qualitative inquiry is naturalistic and inductive in an attempt to make sense of the experiences people have in relation to a particular phenomenon (Mayan, 2009).

In this study providing parents opportunity to share their experiences with SCPs will provide them with a voice and opportunity to contribute to the generation of knowledge in the area of childhood cancer survivorship. To do this a qualitative descriptive methodology is used that aims to elicit patterns and themes within a phenomenon by minimizing interpretation and reporting the data based on the perceptions and experiences of the participants (Neergaard et al., 2009).

Qualitative Description Design

The research goal will reflect a level of methodological congruence to indicate an extent of description and interpretation. A qualitative descriptive approach is one that provides a "rich, straight description of an experience or event" (Neergaard et al., 2009, p. 53). Furthermore, Sandelowski (2000) depicts this method as having less interpretation, less abstraction of data, and a form of categorical inquiry. In providing descriptions of phenomena, the researcher must present the data to accurately represent the events in a manner that is close to the data and in everyday language (Sandelowski, 2000; Neergaard et al., 2009).

Understanding the experiences of parents of childhood cancer survivors with SCPs is an example of a question in which a qualitative descriptive approach would be an appropriate choice. The strength in utilizing a qualitative descriptive approach is in the straightforwardness, as the researcher's goal is to ask, listen and describe the data in a meaningful way (Smythe, 2012). Unlike other qualitative approaches, analysis in descriptive research may not move beyond what the participants communicate, allowing for the emergence of truth as portrayed by the participants (Smythe, 2012).

Participant Recruitment and Selection

Purposive sampling. Qualitative researchers work with smaller sample populations and often use a purposeful method of sampling to gain in-depth information from participants (Glense, 2011). Various types of purposeful sampling strategies exist, any of which could potentially be used in qualitative description (Neergaard et al., 2009). The pragmatic approach intended throughout the research process of qualitative description allows the researcher flexibility to mould sampling strategies that fit the purpose of the research. While different strategies support alternative methods of sampling, in this study of parental experiences with SCPs in the care of their child, a convenience sample proved most appropriate. Purposive convenience sampling displayed worth in this case by offering rich data from a group of participants who offered their experiences with SCPs from a specific study site. In other words, all parent participants for this study received the same type of SCP as they were all clients of one institution. Through purposive convenience sampling it was possible to focus on this study population.

The depth of the data helps subdue threats to credibility within a convenience sample (Creswell, 2013). Additionally, adjusting a sample size to meet the purpose of the study can impact and improve dependability and applicability of the results across the site within the phenomenon of interest (Creswell, 2013).

Recruitment. A purposive convenience sample of a minimum of five parents, of five different children, who had received SCPs related to their child who has survived cancer was the goal of this study. The parents of those children who have survived childhood cancer were selected from a pediatric oncology survivorship program at a tertiary children's hospital where SCPs are used. Permission to access the pediatric oncology program at the tertiary children's hospital was obtained from the site administrator and the research ethics board of the institution prior to accessing eligible participants (Appendix A). Research ethics approval was also obtained from Athabasca University prior to proceeding with recruitment (Appendix B).

A package of materials for potential participants was composed by the researcher. Each package contained an invitation letter describing the purpose of the study (Appendix C), including a section on consent procedure, and details regarding voluntary participation, ability to withdraw at any time, and confidentiality (Appendix D). Reference to the sensitive nature of the topic was also included in the invitation letter. The survivorship program nurse at the site provided these packages to eligible participants from the childhood cancer long-term survivorship program during a routine follow-up appointment.

True to convenience sampling, recruitment of eligible interested participants occurred on a first-come, first-serve basis. Initial attempts at recruitment were aimed at providing potential participants with the contact information for the researcher and asking interested participants to contact researcher via email or telephone to obtain further information on the study. After the distribution of ten packages over a period of approximately one month no potential participants made contact. At that point, revisions to the recruitment process were made. This revision process included a revision to the research ethics application for both research ethics boards, University of Alberta (Appendix E) and Athabasca University (Appendix F). Approval for the revised recruitment process was obtained from both authorities.

Revisions to the recruitment process, and the invitation letter, included shorter interviews that would be conducted by the researcher over the telephone, rather than face-to-face interview that was originally proposed. This revised process was to optimize accessibility and ease for participants. Furthermore, participants were asked for consent to have the clinic nurse provide the researcher with contact information to reach out for participation in the study. Once the researcher was able to contact participants, review of the purpose of the study and opportunity for questions were permitted. For those who expressed interest in participating after this initial contact, verbal consent was obtained and telephone interviews were set up.

Through an ongoing process of data collection and analysis (de Vries et al., 2013), a final total of eight participants were interviewed to collect data that were rich enough to meet the outlined purpose of the study. Eight participants were interviewed during the process of cyclical data collection and analysis to ensure a rigorous attempt at data saturation. The first five participants interviewed did not offer data rich enough for saturation within the emerging themes. de Vries et al. (2013) used this process of thematic saturation, as described by Denzin and Lincoln (2000), as a method of effectively collecting and analyzing large amounts of data in qualitative research. Those participants recruited and selected to participate in the study were required to meet a set of inclusion and exclusion criteria.

Inclusion criteria.

1. Parents who are the legal guardians and primary caregivers of children who have been diagnosed and treated for childhood cancer.
2. Parents whose children have been off treatment for cancer for a minimum of 2 years.
3. Parents who have received a survivorship care plan (SCP) as part of ongoing follow-up care for their child.
4. Parents whose children are currently between the ages of 3 and 17, and remain under the primary care of their parent.

Exclusion criteria.

1. Parents who do not have custody of their children or are not the primary caregiver.
2. Parents whose children are currently over the age of 18 and no longer under the direct care of their parents.
3. Parents whose children are considered to be in palliative care and who have cancer that is deemed currently untreatable with chemotherapy, radiation or surgical intervention.

Data Collection

Within a qualitative descriptive study, data collection techniques are aimed to uncover the experiences of participants through minimally structured open-ended interviews (Sandelowski, 2000). This process is an ongoing congruent method of data collection and analysis that is complete once sufficient data is achieved (de Vries et al., 2013). This was evident throughout the process of data collection and analysis as common themes emerged from the data. Participant interviews were conducted via telephone and at a time determined by the participant in an effort to increase the comfort level of those being interviewed. Consent forms were provided to the participants in the packages developed by the researcher and reviewed over the telephone (Appendix D). Any additional questions were answered by the researcher prior to verbal consent being obtained during the telephone interview. Participants were additionally asked for verbal consent to audio record the interview. This data collection strategy was used to capture as much data as possible for purposes of review and analysis at a later time to fully capture the language and meaning participants convey of the phenomenon. Audio tapes were transcribed verbatim by the researcher post interview.

Once verbal consent was obtained during the telephone interview, semi-structured interviews were conducted with open-ended questions to encourage the participants to elaborate on their experiences. The use of semi-structured interviews in this qualitative descriptive study is appropriate as the researcher is knowledgeable enough regarding the phenomenon to confidently develop the questions but not certain enough to anticipate the participant responses (Richards & Morse, 2013). Interview questions centered around the experiences parents had with the SCPs they have received following their child`s treatment for cancer. Of particular interest were perceptions parents had regarding SCPs and how they thought the SCPs had impacted the care they provide to their child who has completed cancer therapy. Flexibility was maintained throughout the interview process to allow participants to fully elaborate on their experiences, which may have fallen outside of the proposed interview questions. If participants began to veer off topic, including venturing into sensitive topics, the researcher was able to redirect the interview back to the SCPs. Resource materials were offered to participants if counselling or additional support was required after the interview, but all declined. Reiteration that this additional support or additional questions they may have would be available at any point following the interview by contacting the researcher. Interview questions that all participants were asked, aside from the ad hoc questions throughout, are listed.

Interview questions.

1. What is your understanding of the survivorship care plan package you received following your child`s treatment?
2. How have you utilized the survivorship care plan package since you received it?
3. What role has the care plan package played for you in the care that you provide to your child?
4. How prepared do you feel to educate your child about their cancer, treatment and future when they begin to ask questions?
5. What do you see as the advantages/disadvantages of the plans/packages?
6. What, if any, recommendations would you make to improve the care plans/packages?
7. How has the survivorship care plan package impacted the quality of life or health outcomes of your child? Can you offer any examples or stories?
8. How do you share your child's medical history with other healthcare providers, like a family doctor?
9. Can you describe, if any, the value you could see in an electronic or web-based package/care plan?

Participants were asked to limit provision of personal information for reasons of confidentiality, including the name of their child. Any identifying information shared during the interview process were not transcribed directly and identifiers were replaced with either blank spaces or generic terms such as *child* or *husband.*

Data management. Participant contact information is kept separate from the audio recordings and the transcribed interviews, all of which have non-identifying labels attached to them. No information on their child's personal details were required, including name, diagnosis and treatments received. The audio tapes are secured in a locked cabinet in the researcher's home and only the researcher has access. All data collected will be stored securely for a minimum of five years in compliance with the site rules and regulations. Any electronic generated data is stored on the researcher's personal computer and is password protected. All data will be shredded electronically five years after completion of the study. A handwritten researcher reflective journal was kept during this study and it is secured in a locked cabinet in the researcher's home with the researcher having the only access. The journal contains no identifying information within the contents.

Data Analysis

Analysis of the data in qualitative research does not have a definitive beginning or end, but is rather an ongoing, iterative process (Bradley, Curry, & Devers, 2007). Specific analytical procedures can be used to explicate raw data into a representation of the information the researcher wishes to convey through the research study. The analysis focuses on answering the research question: *What experiences have parents of children who have survived cancer had with SCPs?*

The strategy of choice for data analysis in qualitative description is identified by Sandelowski (2000) as qualitative content analysis. This strategy is used to generate codes from the data that are modifiable to represent the data. As Sandelowski (2000) says, "qualitative content analysis is the least interpretive of the qualitative analysis approaches in that there is no mandate to re-present the data in any other terms but their own" (p. 338). Through content analysis, the researcher uses a systematic coding approach to organize a large quantity of data. The aim is to unobtrusively uncover trends and patterns while examining the language and communication structures (Vaismoradi, Turunen, & Bondas, 2013). Qualitative description, with its naturalistic inquiry, depends upon processes of analysis that aim to uncover the phenomenon of interest from within the context in which it occurred (Thorne, 2000). The flexibility and unstructured method of content analysis supports the distinctive nature of each inquiry and researcher (Elo & Kyngas, 2008).

For this study the research question examines the parental experiences of SCPs in caring for their child who has survived cancer, a qualitative content analysis approach allowed the researcher to gather data from the participants and catalogue the data accordingly. The content gathered from the parents was described in a manner that uncovered common themes, and in the end, the researcher remained close to the data and minimized interpretation. Findings from data analysis offer an understanding of a phenomenon of parental perceptions that has not previously been explored. Elo and Kyngas (2008) suggest content analysis as a fitting method for sensitive topics, such as pediatric oncology. This analysis approach allowed for underlying themes to emerge and resulted in insights regarding how the SCP tool impacts the care provided to childhood cancer survivors.

More specifically, Elo and Kyngas (2008) developed a model of content analysis that divides the process into three distinct phases (Appendix G). The first phase of preparation of data involves immersion in the data (Elo & Kyngas, 2008). Immersion involves the researcher becoming familiar with the data to gain insight to make sense and understand what is going on within the data (Elo & Kyngas, 2008). This familiarization is done through a process of reading the data multiple times (Elo & Kyngas, 2008). The second phase of analysis is called organization and this phase includes open coding, categorizing and thematizing (Elo & Kyngas, 2008). Finally, the third phase consists of the categorization of results and reporting of the data analysis process (Elo & Kyngas, 2008). Offering a clear understanding of how the analysis of the data allows for increased trustworthiness and validity of the results (Elo & Kyngas, 2008). The flexibility of this model of content analysis allowed the researcher, within a qualitative descriptive framework, to maintain a pragmatic approach to data analysis.

As the researcher progressed through the analysis of the data, acknowledgement of personal biases and previous knowledge of the phenomenon became evident. Such in qualitative research the researcher is the instrument of data collection and analysis, self-reflection and knowledge of personal research biases is essential. Use of methodological journals through the process of reflexivity facilitated reflection and acknowledgement of that learning process. Creswell (2013) identifies reflexivity as a concept "in which the writer is conscious of the biases, values, and experiences that he or she brings to a qualitative research study" (p. 216). As suggested by Creswell (2013), the researcher not only needs to explore experiences of the phenomenon but also needs to share how these experiences may form interpretations. This researcher self-analysis and reflection, garnered through the keeping of a reflexive journal throughout the research process, is further elaborated on in Chapter 7.

Ethical Considerations

As noted earlier, for this study ethics approvals were obtained from the children`s hospital research ethics board (Appendix A & Appendix E) and from the Athabasca University Research Ethics Board (Appendix B & Appendix F). Ethical considerations can arise at any point during the research process, including the recruitment and sampling phase and the data collection phase. Special consideration within this study was aimed at protecting confidentiality of the participants. Participant names were coded and in the transcriptions and thesis participants are referred to as Participant 1, 2, etc. The name of the organization where the children received care will not be shared. Full disclosure of the research purpose was included in the information package given to potential participants during the sampling phase. Following participant consent and interview, time was allocated to allow for any questions the participant had for the researcher. The researcher additionally provided the participants a contact number to reach the researcher if they have any further questions or concerns following the interview. No parents made contact with the researcher following the interview.

Due to the potentially sensitive nature of the topic, additional resources were offered to participants at the end of the interview. Resources included community support groups, online support and educational resources, and the contact information of counsellors. Additionally, participants were informed that their participation in the study would remain confidential. However, the survivorship team at the site is aware that some of the families in their care may have participated in this study and are available for additional support at the discretion of the participant.

Conclusion

This chapter reviewed the overall research design and process for data collection and analysis in this study of parental experiences with SCPs as tools in providing care to their child who has survived childhood cancer. Use of a qualitative descriptive approach elicits straight descriptions of a phenomenon that allow the researcher to be guided in the use of this methodological process. Challenges and revisions to the recruitment process are identified throughout while maintaining ethical considerations. The cyclical nature of data collection and analysis is described within a model of qualitative content analysis developed by Elo and Kyngas (2008), leading to the presentation of results in the ensuing chapter.

Chapter V

Results

The purpose of this study was to understand parental experiences with survivorship care plans (SCP) in managing the health outcomes and quality of life for their child who has survived childhood cancer. Utilization of a qualitative content analysis process to reflect the experiences of eight participants revealed three main themes and seven subthemes (see Table 1). The main themes are: *SCP an Important Source of Information, Reliance on Staff,* and *Varying Emotions of Cancer Survivorship*. The seven subthemes are: *Knowledge of Long-Term Effects, Good to Have if Needed, Reliable and Individualized, Trusting Relationships, Models of Survivorship Care, Fear of the Unknown, and Moving on With Life*. Throughout the discussion of the findings enmeshed within the personal accounts of these experiences, the data is enriched and supported with current literature. Verbatim participant comments are used along with the literature to support the themes identified during the interview process.

Participants

Data collected from eight participants was completed via semi-structured audio recorded telephone interviews. Prior to beginning the interview the consent form (Appendix D) was reviewed and verbal consent was obtained from all participants, including consent to audio record the interview. Participants were reminded to limit the amount of personal identifying information provided to ensure confidentiality was maintained. As interviews were transcribed, participants' identity was concealed. Each participant was given a code and are referred to in the thesis by numbers, *Participant 1 (P1), Participant 2 (P2),* etc. As themes were revealed during the transcribing and concurrent analysis of the data, literature searches were completed to enrich and support the data presented. Table 1 represents a layer of analysis that depicts the descriptions found throughout the interviews.

Table 1

Representation of Main Themes and Subthemes

Main Themes	**Subthemes**
SCP an Important Source of Information	Knowledge of Long-Term Effects Good to Have if Needed Reliable and Individualized
Reliance on Staff	Trusting Relationships Models of Survivorship Care
Varying Emotions of Cancer Survivorship	Fear of the Unknown Moving on with Life

SCP an Important Source of Information

One of the first questions asked of the participants was to elaborate on their understanding of the purpose of the SCP they had received when entered into the long-term survivor clinic after two years of being off treatment. The consistent theme from all participants was the importance of information available to them within the SCP. The breadth of this theme was manifested through three subthemes *Knowledge of Long-Term Effects, Good to Have if Needed,* and *Reliable and Individualized.*

Knowledge of long-term effects. This first subtheme encompasses a variety of perceptions parents described about their understanding of the SCP. As recommended by the Children's Oncology Group (2007) one of the key services of long-term follow-up programs is to include in the SCP education materials for survivors about their disease, treatments received and risk for long-term effects. Nearly all participants relayed their understanding of the purpose of the SCP was to provide a source of information and offer knowledge related to the treatments their child received. Responders described the care plans as support to help understand any long-term effects and information on what to observe for during the recovery process. Participant 4 illustrated her comprehension of the care plan as,

> It just outlined everything that [she] had gone through on her treatment, like different symptoms and things that may happen. I remember certain things about her saying, pointing out the different radiations she had and the amounts that she had were within acceptable levels. You know, stuff like that. Outlining what she had gone through and things that might come up in the future in response to those treatments.

Other common perceptions of the goal of the SCP found in the data related to the importance of having the knowledge related to their child and knowing it is accessible to them. Participant 7 believed that having the information in the SCP afforded them power, allowing them to focus their energy on the next steps. A number of participants stressed the significance of having information and noted that having the SCP consoled them in a sense. In other words parents commented that having the information provided by the healthcare personnel who cared for their child gave them a sense of security. One participant recalled reviewing the information in the SCP with other parents, "we were just fumbling through the packages and had to just read, read, read, read. And I can see they felt comfort in as much information as they could get" (P7).

While many participants described the information as useful and valuable to have, most felt overwhelmed with the amount of information provided to them at the time they received the SCP. Participant statements included: "It was a lot of information at that time, of course, it was overwhelming" (P7); and "...there is a lot of information in there" (P4). The recommendations for content to be provided in the SCPs include, but are not limited to, a personalized treatment summary, a list of late effects the child is at possible risk for, other challenges that may be faced, recommended ongoing care, and additional educational and resource materials (Salz et al., 2012; Palmer et al., 2014).

A literature review by Salz et al. (2012) explored various stakeholder perspectives of SCPs, including the cancer survivor. A common theme that emerged for Salz et al. (2012) was the amount of information being delivered and the manner in which it was delivered, including timing and language. Survivors reported being unable to focus on the large amount of information provided to them, including confusion arising from the use of medical terminology and jargon (Salz et al., 2012). In the review by Salz et al. (2012), most survivors valued the SCP and information provided, however, variation existed among perspectives regarding the amount of detail required and preferred timing of delivery of the SCP.

Good to have if needed. While all the participants, in various degrees, valued having the information in the SCP available to them, most confirmed in the interview they did not utilize it. Despite a review of the SCP by the long-term survivorship clinic nurse upon receipt of the package, the general consensus among participants was that it was good to have, if needed, but they did not refer to it often, if at all. The only time some parents had looked at the material in the SCP was when it was being reviewed with them by the clinic nurse when they first received the package. One participant shared, "I really didn't read through it but I know it's there if I needed it....it's a nice package to have if you need it" (P8). Another participant shared that "It was just information that I could have on hand if I needed. I've looked through it here and there" (P3). Still, another participant added, "I haven't really delved into it too much and looked at it. I just glanced at it when we got home and then put it aside and didn't even really get into it in detail" (P4). Throughout the interviews it was evident that all participants valued the information provided to them yet when asked how they used the SCPs, were unable to offer clear examples of use. Those participants who were able to describe times when they used the contents of the SCP mentioned they used it when their child had a specific health need at a specific period of time. One parent recalled a period of time when the package became useful after receiving it approximately 6 years earlier:

> They were doing echocardiograms every 2 years and they noticed, I don't remember exactly what it was, just something about the ECG, so they were watching it closer. So I just referred back to see and read what else was in

> there. And what they had to say about his health in this package. And between that and his appointments in [the city], it kind of covered everything. (P5)

On the other end of the spectrum, one participant felt the information provided in the SCP, while information to have on hand if needed, was not very helpful (P3). Participant 3 had referred to some of the information in the package related to learning disabilities and felt it was not relevant to her child,

> There's a pamphlet in there to do with educational issues and it's pretty silly because it speaks of laws and rights of students in the United States and testing recommendations that they say should have been done at a certain time but haven't been done. And, doesn't really apply to us. Like, I'm getting the testing done now but it's four years later.

Further Participant 3 commented that the information was very generalized and non-specific. Participant 3 did not recall receipt of a specific treatment summary related to her child's diagnosis and treatments as part of the SCP she received.

Reliable and individualized. While Participant 3 did not recall receiving a treatment summary for her child in the SCP, the other participants stated they had all received a copy of their child's diagnosis, chemotherapy treatments, radiation treatments, and surgical procedures. The inclusion of the personalized treatment summary is strongly recommended by the Institute of Medicine and Children's Oncology Group (COG, 2008). Additionally, Bhatia et al. (2009) recommend the generation of an effective and thorough SCP to reflect the needs of the survivor and their family, inclusive of the treatment summary, patient education materials, and individualized follow-up care based on the COG-LTFU Guidelines. The education materials are known as "Health Links" that accompany the COG-LTFU Guidelines within the SCP. The "Health Links" are designed to specifically meet the healthcare needs of each individual (Bhatia et al., 2009).

Participants in this study recalled the "Health Links" within their SCP packages and related that it was important to know the information being provided to them was from a reliable, medical source. Participant 5 stated the package "tells you where they get their information from." Another participant shared, "I try not to Google, it always gets you into trouble, right? So the book is somewhere where I would go to get correct information" (P2). Salz et al. (2012) recognize that not all SCPs are created equal and there is variability among concise summaries and recommendations versus a broader scope to allow for a more comprehensive summary of information. Based on these results, Salz et al. (2012) recommend that each institution develop SCPs that meet the various needs of the institution and the survivor.

The participants in this study reflected on the usefulness of having a wide range of information that is relevant to their child. As Participant 2 said, "It is a place to check that has kind of a complete list of information that is tailored toward your child" (P2). Another participant revealed, "I really like the fact that there's a write up about all her doctors, about what chemicals she had to go through, all the procedures" (P8). The SCPs also include a follow-up appointment and tests schedule for most of the participants, with Participant 2 sharing that, "It was good to just know what the schedule is. It was helpful to have them follow her."

While most participants valued the information sources and detail, two participants expressed disappointment in the lack of individualization of the SCPs. Participant 3 commented on the content of the SCP saying that, "it's all very generalized, like if you come across this problem, here's this information about it. But it may not apply directly to your situation...I think it could have been more specialized to her treatment". Another participant shared her experience related to understanding of the information:

> When you read through the packages a lot of it is medical terms, that a lot of it, as a normal parent, are like 'hmmm, I don't really understand half of this'. Right? So I mean, basically, normal parent questions are: *What are the chances of it coming back? What do I look for?* Like just the normal stuff. A lot of stuff in the package, I'm looking at it right now, I never have questions about half the stuff in here. (P8)

A study by Firth et al. (2013) of childhood cancer survivors and their families' views on treatment summaries also indicated parents reported receiving information that was neither age nor language appropriate. Furthermore, the study by Firth et al.(2013) found a discrepancy among survivors and families and the breadth of individualized information received. Similar to the participants in this study, the participants in the study by Firth et al. (2013) believe that while comprehensive information is important, the value of individualized care plans and summaries cannot be stressed enough.

The first theme identified, *SCP an Important Source of Information*, uncovers the perception of the purpose of the survivorship care plans as evidenced through parental experiences and understandings. Recognizing the SCPs as a valuable source of information in the care of their child is significant to document. The three subthemes embedded within the theme offers a further description of how that information is perceived and utilized to maximize health outcomes and quality of life for their child. Further analysis of this data leads to the next theme, *Reliance on Staff*, which offers some insight about how the information received in the SCPs is relied upon.

Reliance on Staff

The impact of childhood cancer on a family is significant and can have lasting impacts on relationships that are formed during the journey through the cancer trajectory. There is a degree of trust that is formed on many levels within the relationship with a particular focus on support. Furthermore, various models of delivery for follow-up care exist and can impact continuity of care and access to resources (Friedman, Freyer, & Levitt, 2006). As participants shared their experiences, the common theme of *Reliance on Staff* became evident, with two underlying subthemes of *Trusting Relationships* and *Models of Survivorship Care* emerging.

Trusting relationships. Amid discussions about experiences with SCPs participants shared a common belief that when they sought out information, the first place to turn would be to the staff at the long-term survivorship clinic rather than turning to the SCP. One of the participants commented although she could see value in the SCP, "going in personally to see the doctors is more relieving to us than actually just pieces of papers shoved in the filing cabinet" (P8). Other participants felt that unless there was a pressing issue with their child's health, they would wait for their next follow-up appointment at the long-term survivorship clinic to ask the healthcare team their question. These participants clearly had more trust in the people who provided them with the SCP than trust in the content of the SCP.

Further, Björk et al. (2005) studied the lived experiences of families faced with childhood cancer and revealed that prolonged interactions with staff relayed a sense of safety and security. Participant 8 expressed that having information from the survivorship clinic team made her feel "like the doctors and everyone still cares about you after." Additionally, Participant 3 conveyed, "I get more benefit from talking to the nurses and doctors there rather than the actual package."

As a number of the participants felt more comfort in speaking directly to the healthcare providers in the clinic, there was also an underlying expectation that the team arrange all follow-up appointments and tests. One of the main purposes of the SCP is to act as a communication tool for the provision of care to meet the needs of survivors, including a schedule or roadmap of services required (McCabe et al., 2013). As outlined by Stricker et al. (2011), "The survivorship care plan acts as a guide for outlining and coordinating follow-up care, including surveillance tests, recommended health behaviors and resources, and education about and monitoring of potential long-term effects of cancer treatment" (p. 359). Although recommendations for, and the inclusion of, the follow-up schedule in the SCP parents continued to rely on the long-term survivorship clinic team to arrange those appointments and tests.

Despite the inclusion of these individual follow-up schedules in the SCP for most of the participants, a clearly evident theme that emerged within the data was that the family did not feel responsible for the coordination of any follow-up appointments, including those with specialized services. Participant 5 acknowledged, "I have never arranged any [appointments]. Like when he was due for an echocardiogram, I usually would call a month ahead just to confirm that they have made it." Another participant affirmed that if communication of disease and treatment history was required between her child's family doctor and the oncologist, it was the responsibility of the oncologist to relay that information. The reliance on the staff within the long-term survivorship clinic may be a reflection of the type of model of survivorship care practiced at this particular site. This theme is further explored and analyzed in the following section.

Models of survivorship care. Participants were not asked any questions pertaining to the model of care delivered at their site. However, data collected during the interview process demonstrated evidence that the method of coordinated care of services to manage survivorship care at the clinic had a significant impact on parental perceptions of their SCPs. Various models of survivorship care exist, all with unique advantage and disadvantages. The site of this study delivers survivorship care using a cancer center-based model in which a dedicated long-term team is coordinated, within the same center in which treatments occurred (Freidman et al., 2006). As mentioned under the subtheme of trust, this model elicits a level of comfort and trust in the patient as there is a continuity of care from diagnosis to long-term follow-up (COG, 2007). Participant 4 described a lack of pediatrician involvement as "we've been at the [hospital] often enough that if anything does pop up, we are just there enough that we just get the doctors there to check her up." Participant 5 also affirmed that if "there have been no pressing concerns, we just wait to go to the hospital for that."

The literature on models of survivorship care do recognize that there is no one best fit for all programs. Stricker et al. (2011) identify many challenges in survivorship care, one being the many variables of patient, provider and system, that impact coordination of care for these survivors. Participant 2 identified her child as having more complex medical needs and thus requiring a higher level of coordinated services to meet her child's complex needs. "She's had lots of people that follow her... I would probably ask at her next visit. She sees her pediatrician more often than she goes to the oncology clinic so I would probably just ask her doctor" (P2). This type of model is more representative of a shared care, or hybrid, model which involves a provision of survivorship care that is the responsibility of both the primary care provider and the oncology team (Freyer, 2010).

During the interviews of participants it became evident that the reliance on the long-term survivorship team at the clinic stemmed from a model of care that promotes continuity from the acute phase to long-term. Ultimately, Friedman et al. (2006) recognize that "there is unlikely to be a single model that is optimal for all circumstances...The effective model must be flexible enough to provide continuity of care with appropriate surveillance and access to specialized treatment in an age-specific environment" (p. 164).

A willingness to share their experiences was obvious among the participants of this study. Each had their own experiences with the SCPs and with the healthcare team in the survivorship clinic that formed various relationships of trust and reliance. Furthermore, with each interview completed a wide range of emotions were drawn upon either from the past or present. This theme of *Varying Emotions of Cancer Survivorship* is described in the next section.

Varying Emotions of Cancer Survivorship

Childhood cancer can be a traumatic experience for everyone involved, with feelings following treatment ranging from "relief to anxiety to fear" (National Cancer Institute, 2013). At various points during the interview process, themes emerged from the data representing individualized experiences throughout the cancer trajectory. All participants in this study were in the survivorship phase and exhibited varying emotions, with subthemes emerging as *Fear of the Unknown* and *Moving on with Life.*

Fear of the unknown. Various forms of fear can exist in any situation with any individual. The Children's Oncology Group (2008) recognizes that cancer in children is always a difficult experience and moving toward the future can be anxiety-provoking. When parents were asked about the information within the SCPs they received, a number of them related a sense of fear from that knowledge and information in the SCP package. Participant 5 recalled, "I read it just after we got it.

And it scared me because of everything we had just gone through and now we have all this to worry about." When reviewing the SCP, Participant 2 shared,

> There was lots of scary type of information. There are all the things that could happen long-term... like the consequences of having the chemo she got. There was all the information about what to watch for in the future. About things that can go wrong when you have those drugs.

Participant 2 also remembered feeling shocked and stressed about all the information and constantly being reminded of all the things that could happen. She even shared that the risks long-term proved a longer list that the immediate side effects of being on treatment (P2).

A recent review of the literature by Ljungman et al. (2014) reported various impacts on psychological health related to the coping for parents of childhood cancer survivors. Results indicated "elevated levels of psychological distress such as posttraumatic stress symptoms (PTSS), depression, anxiety, sleep disturbances, somatic symptoms, fear of recurrence, excessive worry, and fatigue" (p. e103340). Challenges exist not only among parents of childhood cancer survivors, but with all members of the family. Participant 8 recalled sharing the information in the SCP with the child's grandparents and remembering "the grandparents didn't even want to look at it because it was too hard on memories."

Participant 2 went on to say that the SCP was,

> Quite stressful reading through it again because it was a review of all the things I had heard in the past and it had been quite a few years and I hadn't thought about the future for her. And that part was scary.

During one of the interviews, Participant 7 opened up, "Definitely you are asking me to think back to a place that was not a good place." Participant 7, in speaking about the usefulness of the SCPs, expressed the individual need for information that varied among parents, "They [other parents] had that at their hands and for me it just wasn't what I could do at that... not a good thing for me at that time. So there is value in that."

Coping strategies will vary among individuals and families who have been impacted by cancer, and parents of childhood cancer survivors do report higher levels of emotional distress (Hoekstra-Weebers et al., 2012). Hoekstra-Weebers et al. (2012) also demonstrated that parental psychological distress did decline over time. Additionally, findings from a study by Bruce et al. (2010) on childhood brain tumour survivors and their parents reported post-traumatic stress disorder symptoms, characterized by "re-experiencing of the traumatic event; persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness; as well as persistent and heightened arousal" (p. 244). During the interview process, a number of participants made mention of the desire for *moving on with life* and this is discussed in the forthcoming section in more detail.

Moving on with life. Throughout the interviews, parents discussed the concept of *moving on* beyond the cancer experience. When one participant was asked about how they have utilized the SCP in providing care for their child, the response was,

> I guess I haven't read enough yet. I guess at this stage when everything is kind of going good or you think things are going good, you just don't want to read any more. Or hear any more about cancer. (P6)

Participant 4 related similar feelings,

> Maybe as a person gets more comfortable with everything then maybe it's okay to look at it and read some of the stuff. So maybe in my mind set, that's why I haven't looked at this stuff. Do I really want to know that there's still issues that can come up? You know, like you kind of put your mind at a place where you really don't want to know for a while. We are good right now and I just don't want to bother looking at any stuff.

As discussed by Bruce et al. (2010), post-traumatic stress disorder can be characterized by avoidance behaviour related to the traumatic event. While various factors can contribute to the development of post-traumatic stress symptoms, or even heightened anxiety, the participants of this study were able to reflect on potential rationale for ineffective use of SCPs in managing the care of their child. Participant 8 elaborated on the notion of *moving on with life* in relation to survivorship care and the SCPs,

> I honestly just don't, I just skimmed through it when we got it then tucked it away. Because I try not to brew on when she was sick. Because we've tried to

> move on, and it's hard. When you have questionnaires like this, or you go to the doctors, it just feels like you're never moving on.

Throughout the interviews, participants continued to make remarks that stood out regarding strong emotions related to the desire to move on in their lives. Participant 4 conveyed a strong yearning to "get past all this stuff and place, then it's really kind of like... I just want to put this behind me and just live". Participant 7 relayed a longing of, "You just want to hear the 'ok' and just carry on with life."

When participants were asked about educating their child about their disease, treatments and future risks, most conveyed a strong support of doing so. A couple of parents had already begun to answer their child's questions but others seemed caught up in the notion of *moving on with life*. Participant 7 shared that her son does not talk about it or ask questions, that "he's kind of moved on." Furthermore, Participant 7 articulated that perhaps her son was reluctant to ask questions because they never talk about his cancer experience with him. Participant 4 also shared a conversation with her daughter, "You are alive and we will deal with that [long-term effects] when the time comes. You are only 13 so we have lots of time to deal with issues like that."

Exhibiting strong emotions throughout the cancer trajectory, including long afterwards, has been established as expected within this population (Bruce et al., 2010; Hoekstra-Weebers et al., 2012). A study of mothers accompanying their older children to follow-up appointments revealed a sense of apprehension of mothers about their child's health and well-being, accompanied by a sense of uncertainty about future health (Doshi et al., 2014). Recognition that the cancer experience is traumatic and those impacted by it can be effected both physically and psychologically for a lifetime is evident.

Conclusion

The results from the analysis of data from eight participants revealed three main themes and seven subthemes related to the experiences parents of childhood cancer survivors have had with SCPs. The main themes are: *SCP an Important Source of Information, Reliance on Staff,* and *Varying Emotions of Cancer Survivorship.* The subthemes presented as: *Knowledge of Long-Term Effects, Good to Have if Needed, Reliable and Individualized, Trusting Relationships, Models of Survivorship Care, Fear of the Unknown,* and *Moving on With Life.* In addition, current literature was included to further understanding of these themes. The explicit descriptions of these participants will be further utilized in the next chapter to expand on the current knowledge of SCPs. In discussing implications for survivorship care and future recommendations, current literature will be interwoven with the data.

Chapter VI

Discussion

The previous chapter displayed results from a content analysis of the data describing the experiences parents of childhood cancer survivors have had with survivorship care plans (SCP) in relation to the health outcomes and quality of life for their child. This chapter will elaborate on the results to include an integration of the literature with the major themes and subthemes identified. In addition, a review of implications of the findings and recommendations for the future direction of survivorship care and research are described throughout.

The literature review in Chapter 2 provided an overview of childhood cancer survivorship with a focus on related late effects of cancer and its treatments and a discussion of the value of personalized educational tools for survivors and their families. An evaluation of the current state of survivorship care and SCP tools identified barriers in how this care is delivered to the survivor and their family. The inconsistencies in the literature related to use of SCPs and identified barriers to coordination of care for childhood cancer survivors surfaced the question: *why?* More specifically, with such wide support for structured communication tools, such as the SCP, why do such challenges remain in overcoming the barriers to effective use of SCPs? This question redirected focus back to the parents of the child, who are in a primary position to utilize the SCP in the case of pediatric cancer patients. These parents are also most knowledgeable in terms of the impact of the SCP on their child's health outcomes and quality of life. This discussion chapter relates the data collected from the interviews to current literature to further understanding of the current state of SCP use and effect in pediatric populations and to make future recommendations for enhanced survivorship care.

Development and Delivery of SCPs

One of the main themes identified from the data collected during interviews included the information contained within the SCP received. While all participants agreed the purpose of the SCP was to offer knowledge of long-term effects, perspectives of the usefulness of that information varied from parent to parent. Further elaboration to understand this variation in parental perspective is presented here with consideration of factors such as content, timeliness of delivery, review of materials, and individual learning needs. Additionally, consideration of the needs of healthcare providers as an important factor in the provision of SCPs is reviewed.

SCP content. While recommendations put forth by the Institute of Medicine include core elements to be included in SCPs there is no standardized framework for a SCP (Ganz et al., 2008). Broad frameworks may offer flexibility in developing SCPs, however, Stricker et al. (2011) suggest that less comprehensive plans may be of value when many variables need consideration. Some participants in this study did share that the amount of information provided to them in the SCP they received was overwhelming and that not all information included was relevant to their child. Participant 3 said of the SCP,

> It was just information that I could have on hand if I needed. I've looked through it here and there. Like right now we are having a problem with her

> having learning disabilities related to the cancer, or the chemotherapy. So I went through the package again and it's really not very helpful... it doesn't really apply to us. It's all very generalized. Like if you come across this problem, here's this information about it but it may not apply directly to your situation.

Another participant, P8, shared that preference for the content in the SCP may vary from person to person,

> It depends on the individual. Some parents might like all these, looking at nutrition after, dentist after... Me, personally, I mean, I just like the personalized thing of it. I didn't really need all the pamphlets to go with it.

The pamphlets Participant 8 was referring to are the educational materials, "Health Link", that are aimed at enhancing health promotion and offer explanations of health risks in lay language (Bhatia et al., 2009; National Cancer Institute, 2014).

Despite following recommendations as indicated by Bhatia et al. (2009) and the National Cancer Institute (2014) for content in SCP to be simple and straightforward, at least one participant felt there were too many medical terms that were not easily understood (P8). Furthermore, Participant 1 revealed that his English was not very strong and that he had trouble understanding some of the questioning throughout the interview. If this parent had challenges understanding spoken English it is possible that he would also have a challenge reading printed materials written in English. These findings may demonstrate a need to evaluate not only what content is included in the SCP, but also the reading level of the content. Perhaps consideration needs to be given to providing printed materials in the first language of the parent either in written or in spoken form. In addition to content of SCPs, a review of the method and timeliness of SCP delivery to survivors and their families requires consideration.

Further, consideration needs to be given to the quantity of material included in the SCP. A review by Salz et al. (2012) reveals variability among adult survivors regarding the amount of detail provided in their SCP, with most adults preferring more detail than less. It is reasonable that parents of childhood cancer survivors would also likely have variation in the amount of detail they would see as optimal in their SCP.

Method and timeliness of SCP delivery. Based on recommendations by the Institute of Medicine and Children's Oncology Group to disseminate comprehensive summaries and follow-up care plans to survivors of cancer (Stricker et al., 2011), all participants received some form of SCP. Only two participants did not recall receiving a personalized treatment summary as part of their SCP. The process for timing of delivery of the SCP is based on recommendations following the COG-LTFU Guidelines, that suggest use of the SCP "beginning two or more years following the completion of cancer therapy" (COG, 2008). Salz et al. (2012) found variability in the preferred timing of delivery of SCP among survivors with some preferring to receive the SCP at the end of cancer treatment and others preferring to receive the SCP well after treatment completion. Participant 2 shared that receiving information from the SCP package earlier in treatment, rather than after completion of therapy, may reduce the level of surprise,

> I think hearing the things in the package before. Yeah, hearing more information like that while they are on treatment, then afterwards. Before you get to long-term survivorship, as reminders, might make that binder a less of a shock.

Recommendations by Hewitt et al. (2003) to increase survivor awareness of risk for the development of late effects includes beginning discussions about late effects at the onset of cancer diagnosis. These authors support the views of Participant 2 who commented that receiving relevant information throughout the treatment process would have been most beneficial.

In addition to consideration of timeliness for SCP delivery, method of delivery requires attention. From Participant 1 who identified struggles with English, to Participant 8 who shared that the information was not helpful as she was "not a huge reader" it is clear that not all parents learn optimally by reading a package of learning resources. The Institute of Medicine recommends that all instructions be in writing (Sabatino et al., 2013). Benefits to paper/printed delivery of educational materials were identified by Salz et al. (2012) including the value of having information on hand in a tangible form that can be shared with others. Furthermore, verbal presentation of information was found to be overwhelming to recipients of that information (Salz el al., 2012).

Perhaps consideration should be given to using multiple formats for delivery of the contents of the SCP. In such a scenario various factors, including level of education, individual learning needs and personal preferences could be addressed.

Firth et al. (2013) encourage the use of multiple formats for delivery, including "a wallet-size summary, for easier accessibility, information in other languages, and audio or visual formats for those with learning difficulties and visual impairments" (p. 195). Another possibility for SCP delivery is electronic or web-based alternatives.

Electronic access to SCPs. When participants were asked their thoughts on the implementation of an electronic, or web-based, SCP to meet their needs in promoting positive health outcomes and quality of life for their child, there was a general consensus that this would be beneficial. Five participants agreed that a personal online account where they could access SCP materials would allow for ease of access of information. Participant 2 shared that her SCP was currently not in her possession due to moving between homes and is not readily accessible. In the case of Participant 2 having electronic access to the SCP would eliminate access issues.

The notion of electronic SCPs is one that has been explored readily in survivorship care in recent years. Various studies have indicated that electronic access to SCPs may improve access for survivors and improve gaps in communication among survivors, families and healthcare providers (Horowitz et al., 2009; Salz et al., 2012; Stricker et al., 2011; Vickers et al., 2010). Participant 4 related access to an electronic SCP to timely communication,

> As much as I say I know about the basic stuff about her, there are things that when she was going through treatment, like I said, that the doctor's mention something... maybe I hear it but I might not have taken it in. And maybe that's something her family doctor would find useful in the future. Yeah, that is

> definitely something that could be useful... I definitely think it would be valuable to have access, especially to others in the medical field to be able to.

In addition to improvement in access and communication, electronic SCPs could potentially provide more current, up-to-date information that is individualized to each survivor (Horowitz et al., 2009; Stricker et al., 2011). In an area such as pediatric cancer care where research is ongoing and evidence-informed practices change often there is potential that information provided to parents could out-date often. Survivors, families, and healthcare providers would be reassured the information they are accessing is the most current and applicable to their care needs. For example, Participant 8 expressed the advantage of an electronic SCP,

> Just so that it's updated more often. Cause I mean these care packages, how long has it been since this information was updated? I mean, it could be years and they could have new information but she's already been in remission for four years and had these pamphlets. Well, how do I know if it is still up to date?

The site of this study is a COG-designated institution. COG recently developed an application called *Passport for Care*® that offers an interactive electronic SCP format. Horowitz et al (2009) describe this tool as one with the "individualized, accurate, and timely health care information necessary to maximize their health potential" (p. 110). The *Passport for Care*® is continuing to be evaluated and revised and could be a feasible option to engage survivors in participating and managing their on-going care (Poplack, Fordis, Landier, Bhatia, Hudson, & Horowitz, 2014).

Consideration of adopting an electronic SCP would require thoughts about survivors and families who do not have access to a computer or the internet, those with less education and perhaps lacking digital or technical literacy, system security, and institutional resources for implementation of this tool (Salz et al., 2012). While the goal of electronic SCPs is to create individualized care plans that enhance quality of care and health outcomes of survivors, there are opportunities within the *Passport for Care®* application for individualized education resources that are designed to support both survivor and healthcare providers (Texas Children's Cancer and Hematology Centers, 2014).

Healthcare provider education and support. The participants described a strong sense of support from, and reliance on, the healthcare team at the long-term survivorship clinic. Many parent participants acknowledge that they often sought information from the team before looking at the SCP. Understanding these types of behaviours are important for providing high quality survivorship care. It is also important to understand that the healthcare providers need ongoing education and support to fulfill their roles because no matter how informative and accessible the SCP is parents are still likely to contact the healthcare providers directly for information and support. A SCP simply cannot fully replace ongoing communication with the healthcare team.

Given the challenges in coordinating care for survivors and their families, it is evident that emotions continue to play a major role in providing ongoing support to this population. In doing so, the survivorship long-term clinic teams will require ongoing support and education to ensure they are equipped to provide that emotional support. Klemp, Frazier, Glennon, Trunecek, and Irwin (2011) report most nurses do not receive formal education related to oncology and survivorship care and identified the highest need in "managing emotional issues and cancer screening and surveillance, as well as complementary and alternative therapies" (p. 239). As advancements in treatments are made and more children are surviving childhood cancer, the continuing education needs and emotional support for healthcare providers require attention.

A number of participants relayed a desire to move on with life and beyond the cancer. However, the reality for this population is that they are at risk for developing late effects related to their cancer and treatments. While they need to move on with life, they need to be well informed so that they can be vigilant for late effects. Healthcare providers are in an optimal position to offer education and support but can do so only if their own needs are met. Ruccione (2009) shared the challenge of "finding effective ways to educate survivors to enable them to make healthful choices rather than to fear and avoid follow-up care" (p. 260). Another study by Irwin, Klemp, Glennon, and Frazier (2011) examined the perspective of oncology nurses, identifying the major barriers to providing quality care as lack of time and lack of funding. As survivors and their families continue to rely on healthcare providers to educate and support them, long-term survivorship programs would benefit from ensuring they offer support to their staff educationally and psychologically.

Emotional Considerations of Survivors and their Families

In sharing their experiences of the cancer journey in relation to SCPs participants' responses were evidently filled with a mix of emotions. Psychological barriers that can impact survivorship care have been identified by Henderson et al. (2010). These barriers include survivors having over dependency on family members and high levels of anxiety (Henderson et al., 2010). Equally impactful are the barriers of family members of cancer survivors including, "control, emotional dependency, over-protectiveness, heightened awareness of health issues, and a lack of trust in caregivers" (p. 131). Healthcare providers play a key role in recognizing obstacles in the survivorship phase and must continue to support the needs of the family in addition to the survivor.

Parental psychological effects. As childhood survivors continue to age and transition into adulthood, parents are elemental in supporting and educating their child about their cancer and treatments they have received. Yet this population of parents are faced with their own challenges and the impact of their child enduring cancer has been shown to have lasting psychological effects on them, including depression, anxiety, fear of recurrence, and extensive worry (Ljungman et al., 2014). This construct of post-traumatic stress disorder has been referenced in the literature as one that requires attention in relation to parents of children who have survived cancer.

(Bruce et al., 2010; Henderson et al., 2010; Hoekstra-Weebers et al., 2012; Ljungman et al., 2014).

Varying emotions was one of the overarching themes identified during the cyclical process of data collection and analysis. The underlying subthemes of *Fear of the Unknown* and *Moving on with Life* surfaced as indications of negative psychological effects for parents who participated in this study. In particular, the notion of 'moving on' and 'putting the cancer behind us' raised some concerns that require further investigation and understanding. Five of the eight participants in this study demonstrated avoidance behaviours, including a desire to not think about the cancer and putting it all behind them. The current literature on parental psychological late effects is limited. In a broad literature search on this topic by Ljungman et al. (2014), only 15 diverse studies met the criteria for review. Benefit of further understanding of negative psychological effects experienced by parents of childhood cancer survivors can impact how survivorship care is coordinated. Recognition that the family is at the center of the child's life can impact how healthcare providers offer follow-up care to childhood cancer survivors and their families. Further recognition that the family is at risk for their own psychological late effects from having lived through the experience of their child undergoing cancer treatment is an important consideration in planning optimal care for survivors. It seems that content specific to the potential emotional and psychological needs of parents should be part of the SCP.

Family-centered care. One of the main principles to guide pediatric healthcare is that of family-centered care, defined by the Institute for Patient- and Family-Centred Care as,

> an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care practitioners. It is founded on the understanding that the family plays a vital role in ensuring the health and well being of patients of all ages. (n.d., p.2)

This principle of incorporating the entire family unit into the care of the child can have significant impact on the quality of life for the child. The cancer experience impacts the entire family, with research indicating up to 30% of childhood cancer survivors and their families experience personal, family and social difficulties (Friedman et al., 2006). These challenges in functioning can lead to the post-traumatic symptoms described earlier, which can inevitably lead to avoidance behaviours (Friedman et al., 2006).

One of the responses by Participant 4 stands out as one that has an impact on the family unit and to the ultimate well-being and quality of life for the child and the family, "...that's why I haven't looked at this stuff. Do I really want to know that there's still issues that can come up?" The overall theme of *Varying Emotions of Cancer Survivorship* captures a great deal about of the various emotions felt by parents. Further understanding of these emotions and the role they play in childhood cancer survivorship is warranted. Patterson et al. (2004) conducted a study on the traumatic experience of childhood cancer on the child and the family, recognizing that family responses to stress directly impact the child's responses and coping mechanisms, thus resulting in a cyclical sequence of events. Thus knowing more about the family's responses to the cancer experience, what helps them cope well in the survivorship phase for example, will ultimately also potentially benefit the child.

As participants recounted their experiences with their child's cancer journey into survivorship it became evident that emotions were still intense. The family as a whole must be supported by their healthcare team to ensure optimal health outcomes and quality of life for their child. Harrison (2010) describes one element of family-centered care in pediatrics is "recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families" (p. 336). These quality of life issues can significantly impact how survivorship care is delivered and provision of services to include emotional assessment and supportive services for patients and families is warranted (Friedman et al., 2006). In recognizing the variability in family and survivor needs, consideration of effective models of survivorship care require contemplation.

Models of Survivorship Care

The structure of the long-term survivorship clinic was not discussed during the interviews with participants, however, linking the data collected to the literature revealed the significance of the model of survivorship care that is established and delivered within various settings. A number of the themes identified within data analysis could be influenced by the model of care provided at the particular site where the data were collected. Models of survivorship care can vary significantly from one setting to the next, yet recommendations for essential components remain static. These topics will be explored in this discussion to expand on the current knowledge in the literature while also relating that knowledge directly to the data collected in this study.

Models of delivery. A variety of models for delivery of care to survivors of cancer exist, all with distinct advantages and disadvantages (COG, 2007). Determining an effective model requires several considerations that may be unique to each program of delivery. Some of these considerations include, but are not limited to: number of survivors, diversity of survivor population, geographic location of institution, accessibility of institution, and resources available to the institution (COG, 2007). The Children's Oncology Group (2007) identifies a variety of models as cancer-center, young adult transition, community-based, and needs-based. Within each of these models are more specified models of delivery, including the specialized long-term follow-up clinic (COG, 2007). This long-term follow-up model was the type of model experienced by the participants of this study.

The specialized long-term follow-up clinic is the most common type of model utilized for delivery of survivorship care (COG, 2007). While there are a number of advantages to this model, such as continuity of care and comprehensive, systematic follow-up, Friedman et al. (2006) identify challenges that are evident from comments made by study participants. These include an aversion to returning to the site where cancer treatment occurred due to negative emotional associations, in part expressed by "a desire to 'move on' with their lives" (Friedman et al, 2006, p. 163). Participants in the study shared both a desire to move on and a sense of security within the clinic. While no tension was evident during the interviews in this study between wanting to move on and the security with the long-term clinic as a familiar place, this conflicting relationship may require further exploring. Friedman et al. (2006) also expressed this model of returning to survivorship clinics at the same physical location where they received acute care as providing "an artificially protected environment for survivors and not allow them (or their parents) to develop the skills eventually needed to successfully navigate complex health care systems as self-sufficient adults" (p. 163). In this study of participants they had not been pushed to develop some of these skills Friedman et al. (2006) referred to as the parents did not need to coordinate their own follow-up appointments as this was a service provided by the clinic. Variations among models of survivorship care can impact provision of services to survivors and their families. Consideration of the type of survivorship model with the needs of survivors and their families would optimize provision of services and positively impact survivor health outcomes and quality of life.

Interventions suggested by the Children's Oncology Group (2007) would be to introduce the concept of long-term survivorship care to the patient and their family before treatment is completed. This was suggested by Participant 2 as a means to making the information from long-term survivor clinic less of a shock. Perhaps introducing the idea that parents will eventually be responsible, at least in part, for survivorship care for and with their child earlier in the cancer journey would give parents opportunity to learn skills they will need to function effectively later as the leaders of their child's survivorship phase.

With an ever-growing number of survivors, providing services that are effective to meet the needs of all stakeholders will be a challenge within a specialized long-term follow-up clinic. Further exploration of flexibility within a model of delivery requires consideration in order to meet the diverse needs of this population. While it may be important and beneficial to consider other models of delivering survivorship care a new and more adaptable model needs to adhere to the recommended components for delivering quality survivorship care.

Essential components of survivorship care models. Explicit guidelines for developing a program to meet the needs of all survivors, their families and healthcare providers may prove impractical. Working within the confines of resources available and common survivor needs may be more feasible. Rowland (2005) provided a general framework for a pediatric oncology model of survivorship, including five factors: (1) family-centered, (2) consideration of survivor's age and function, (3) consideration of developmental issues, (4) tailor communication to meet needs and understanding of the patient, and (5) recognizing that treatment impacts patients and families long-term. While there are no set survivorship care guidelines that are a fit for all programs, recommendations are made to include key components in survivorship care.

Friedman et al. (2006) summarizes key components necessary within survivorship care, regardless of model, such as a multidisciplinary team for coordination of care, access to diagnostic monitoring, access to medical and behavioural specialists, survivor/family education, financial assistance, formal transitional preparation, research activities, and appropriate clinical space. This is further supported by the Children's Oncology Group (2007) who recognize these factors, in addition to addressing the psychosocial needs of not only survivors but affected family members. While many of the parents who participated in this study related a desire to 'move on' because everything was 'good' at that moment, healthcare providers are in a primal position to offer education and support about the risk of long-term effects. Addressing the needs of survivors and families goes beyond a package or education session and prompts healthcare providers to ensure survivors and their families are aware that "the risk for late effects increases over time and will likely be exacerbated by co-morbidities related to the ageing process" (COG, 2007, p. 6). Acquiring this knowledge gradually over time during the cancer care phase of the cancer trajectory may give parents time to acquire skills and knowledge and time to adjust to this reality. Such a process seems superior to waiting until the cancer survivorship phase and could have the information provided in a package and specialized clinic at the end of active treatment.

Developing and facilitating a model of survivorship care requires careful consideration of facility resources and patient population. Recognizing limitations of the various models is key to providing quality survivorship care to an ever-growing population. As Friedman et al. (2006) explain, "regardless of the model of care employed, partnership with health care providers across a wide range of specialties is required to deliver optimal care to childhood cancer survivors" (p.162). There is likely no one model that is a perfect fit for one program but the model must be flexible enough to meet the various needs of a diverse population of childhood cancer survivors and their families.

Summary and Implications for Survivorship Care

The findings in this study act as a primary guide to understanding childhood cancer survivorship from the perspective of the parent. While asked to share their experiences related to the SCPs they received in relation to their child's health outcomes and quality of life, experiences shared by parent participants moved beyond the SCP to reveal rich learnings valuable to healthcare providers. Participants described an appreciation for the information contained within the SCP and related the information as valuable, reliable and personalized. Delving deeper into the responses provided, participants revealed a level of reliance on the healthcare providers based, in part, on the model of survivorship care delivered. Additionally, participants displayed an array of emotions related to fear of the unknown and a desire to move on with their lives during the survivorship phase.

From the discussion of the findings, several implications for survivorship care surfaced. One of the key elements of effective survivorship care centered around the development and delivery of SCPs. The findings pointed towards a consistent lack of full utilization of the SCPs by parents. Recommendations in the literature offer strong support for providing SCPs as tools for communication and coordination of care. Guidance and support for the development and delivery of optimized SCPs need to be in place for healthcare providers to provide quality care. In addition, healthcare providers require education and support for providing a specialized service to a unique and diverse population. Healthcare providers need to feel confident in the care they are providing, including competence to deliver survivorship care in a methodical and timely manner. Furthermore, consideration of more broad access to electronic SCPs may impact the future of survivorship care.

Further discussion relayed back to emotional considerations and the long-term psychological effects of childhood cancer on parents. Focus on the needs of the family as a unit in offering survivorship care is significant to the overall health outcomes and quality of life for the survivor. The ability to provide survivorship care demands flexibility and continuity that ultimately meets the unique needs of each survivor and family, as well as the needs and limitations of the institution and the healthcare providers. Various models of survivorship care exist and adoption of a model requires careful consideration.

Recommendations for Future Research

This study has elaborated on the knowledge related to parental experiences with survivorship care in managing their child's health outcomes. Specifically, experiences and perceptions of SCPs were studied. The data collected revealed themes directly related to SCPs, and other themes related to parental experiences with survivorship care in general. As these themes and subthemes emerged, opportunities for future research materialized.

As technology continues to advance and the survivorship population continues to grow at an exponential rate, further exploration of electronic SCPs and the impact of these on health outcomes and quality of life for childhood cancer survivors and their families is warranted. While potential barriers have been identified in the literature, further research into the capacity to adapt SCPs to meet the ever-changing needs of the survivor and their families in an up-to-date, personalized and accessible manner is invigorating. A review of all stakeholders' perspectives related to the development and use of electronic SCPs would be valuable, including the survivor and family, long-term survivorship team, and primary care providers.

In addition to accessibility, format and functioning of the SCP was a forefront of discussion during the interviews. While parents valued having the information in the SCP available to them, none utilized the care plans to the extent that was anticipated in the literature. Future research is required in this capacity to further understand why parents in this model of survivorship care do not utilize SCPs. Perhaps investigations into variations of SCPs among different models of delivery of survivorship care may reveal further understanding in relation to this question.

Finally, for parents in particular, the emotional remnants of cancer treatment are evident throughout the survivorship phase. Research is minimal on the psychological impacts of cancer for parents of childhood cancer survivors and this topic requires further investigation. Symptoms of post-traumatic stress have been shown in this population (Bruce et al., 2010; Hoekstra-Weebers et al., 2012; Ljungman et al., 2014) and the possible effect of parental stress on survivorship care and the quality of life for their child and family is necessary. With this knowledge and understanding, healthcare professionals will be in a better position to provide effective survivorship care to the entire family.

Chapter VII

Conclusion

The experiences of the eight parent participants in this study elaborate on managing the survivorship care needs of their child through SCPs. This descriptive study reveals findings that elaborate on the impact of SCPs not only the survivor and family, but also on the survivorship program. Exploration of these experiences through a qualitative descriptive study enabled rich data to be presented in a rigorous manner. This final chapter illustrates strategies used in the study to maintain qualitative rigour, reveals study limitations, and describes potential researcher bias. Chapter 7 closes with a summation of the contributions of this study to overall childhood cancer survivorship care.

Qualitative Rigour

All qualitative studies require a level of methodological congruence to ensure rigour throughout the research process. Qualitative description has been criticized for a lack of rigour based on an assumption that this methodology is atheoretical and non-specific (Neergaard et al., 2009). Sandelowski (2000) disagrees emphasizing that qualitative description permits flexibility to promote a comprehensive account of a phenomenon, strengthening descriptive and interpretive validity. These forms of validity ensure the proper sequence and meaning of events are portrayed by the researcher through rich descriptions and staying close to the data (Sandelowski, 2000). Further, credibility, dependability, confirmability, and transferability are identified as the gold standard for critiquing qualitative studies (Houghton, Casey, Shaw, & Murphy, 2013).

In this study a number of strategies were employed to maintain rigour throughout the research process while still allowing for flexibility. Particular to qualitative description, Neergaard et al. (2009) suggest specific strategies to enhance rigour, including: purposeful, flexible sampling, accurate transcription of participant perceptions, content analysis to ensure data-driven coding, informant validation, researcher triangulation, and researcher reflexivity. To ensure rigour throughout the process, the research study should "reflect the underlying assumptions and tenets of the approach selected, from conception to implications for practice" (Hunt, 2011, p. 300).

In this study that explored parental perceptions of SCPs based on experiences, the researcher remained close to the data yet recognized bias and previous knowledge of the phenomenon. With a strong background in pediatric oncology, the researcher used techniques of bracketing to reflect on previous knowledge by writing a literature review and reviewing it regularly to compare and contrast with the study`s emerging data (Richards & Morse, 2013). The researcher also created a research journal to note previous knowledge and experiences that may impact data collection and analysis through a process of ongoing reflexivity.

Being explicit in how the interview questions are developed and utilized can enhance rigour. As Hunt (2011) notes, "asking fewer, broader questions can elicit much more relevant and richer information from participants" (p. 298). Nine open-ended questions were used during the interview process to allow for elaboration and further questions to emerge. The research questions used in the study were presented in Chapter 4 and developed to center around the phenomenon of SCPs while allowing for flexibility. This process of developing the research questions aligned with suggestions by Richards and Morse (2013) to ensure the researcher was knowledgeable with the phenomenon yet not enough to anticipate participant responses. Articulating this process of interview question development allowed for the researcher to maintain rigour.

Purposive sampling limits the representation and transferability of the results to a larger group of similar participants (Richards & Morse, 2013). While a purposive convenience sampling strategy can seem to negatively impact rigour, the social reality of childhood cancer survivorship is one that requires attention through the collection of in-depth information and detail to inductively understand the phenomenon. These data are only available from participants who have lived the experience being described. This reality made it necessary for the purposes of this descriptive study to employ a purposive sampling approach.

Validity and rigour are enhanced through the depth of information obtained from a small pool of participants. A minimum of five participants were sought, with a final total of eight participants interviewed to meet the needs of the study and allowing for adequate variation in responses and thematic saturation. In a continuous framework of sampling, interviewing and coding, data were sought until adequate themes emerged (deVries et al., 2013). Thus the sample size and depth of insights provided by study participants resulted in meaningful detailed data enhancing study rigour.

Limitations

Due to the nature of the study, and the requirement that participants provided information in retrospect, may have impacted the clarity and validity of the findings. That is parents interviewed for this study had to recall their experiences with the SCP and some admitted that they had not used the SCP recently. Having to retrospectively remember how they felt or acted could have detracted from the accuracy and clarity of participant comments. Additionally, due to the sensitive nature of the topic, some parents may not recall all of the information related to the care plans or may be unwilling to speak to some topics that arise due to the distress of recollecting an event or experience with negative emotion. The term survivorship care plan may also be one that is used by healthcare professionals, and may not be one that is familiar with the survivors and their parents. That is parents may not have used the same label for the package of resources they were given that the healthcare professionals used. There was potential for confusion regarding what exactly the researcher was asking about. Furthermore, the use of telephone interviews limited the ability of the researcher to read non-verbal cues to assist in capturing unspoken data that might have had important meaning for the study. Further the lack of non-verbal data may have also limited analysis of the data.

In an attempt to minimize potential study limitations, the researcher made efforts to allow participants time to recall their experiences. The interview was undertaken at a time chosen by the participant and the researcher used a non rushed approach while conducting the interview. When participants wandered off topic or seemed stalled in their responses the researcher used questions to redirect the interview and encourage respondents to share their insights freely. Furthermore, language that is understood by participants in lay language and at an appropriate reading level was used throughout the study, including in the information package, to ensure full understanding of the purpose of the research study. For example, SCPs were referred to as the "blue packages" as is the terminology used by the healthcare professionals in the long-term survivorship clinic at this site. Finally, recognition that the research is conducted by a novice researcher with a pediatric oncology background warrants consideration as this is both a potential disadvantage being a novice researcher and a potential advantage having a pediatric oncology background.

Researcher landscape. In this section references to the researcher will be made in first person to enhance authenticity and personalization of experiences. The purpose of this section is to reveal to readers a bit about my experiences as a pediatric oncology nurse and my potential assumptions of survivorship care. Since in qualitative research the researcher is the instrument of data collection and analysis, I believe that sharing the landscape against which these research activities occurred will provide readers the ability to make informed judgement regarding how my experiences and biases might have influenced the findings of the study.

Despite having no experience in pediatric survivorship care, I spent eight years as an acute care pediatric oncology nurse who administered the treatments that, in part, led these children to the survivorship phase of their cancer journey. Through the realization that my experiences may impact judgements in this study, my reflective journal assisted me in shedding some light onto my own journey. Sandelowski (2000) affirms that a qualitative descriptive study is the least interpretive, yet recognizes that "all inquiry entails description, and all description entails interpretation" (p. 335).

Regardless of having no background in survivorship care, I came to the realization through my study and reflexivity that my personal experiences and presumptions could impact how I portray the results of the study to my audience. My own interest in survivorship care peaked when narrowing my research question. I discovered that I have a personal and professional desire to understand the experiences of patients and families who are beyond the acute phase of treatment. I witnessed an array of children and family confronted with cancer. Many had positive outcomes while others faced mortality. This experience led me to recognize that throughout my own journey into studying survivorship care, I held on to my own personal presumption that survivorship was something deemed positive. I believed that families would view this survivorship phase as one with significantly less stress than the anxiety and fear I experienced from them during the diagnosis and treatment phases.

Only through the process of self-interrogation did I come to realize this assumption embedded within my own landscape. Since this realization that the survivorship phase can be for some a very stressful phase, I was able to focus my attention on maintaining openness and being attuned to the emotions of the parents during the interview process. With the realization of the emotional impact embedded throughout the cancer journey, including survivorship, I was able to position myself as a researcher who was open and honest in my own presentation of the results.

Contributions to Survivorship Care

This final layer of analysis allowed for the implications within this study to be interwoven with the literature to add to the current disciplinary knowledge regarding childhood cancer survivorship. Particular focus on parental perspectives and the tools used in managing their child's care was central to this study. Relevant research helps us acknowledge gaps in adhering to the recommendations put forth by the Institute of Medicine to have all cancer survivors receive a SCP to improve health outcomes and quality of life. This study contributed to a deeper understanding of the underlying issue that may, in part, begin with parents who utilize these plans for their child who has survived cancer. The major themes of: *SCP an Important Source of Information, Reliance on Staff,* and *Varying Emotions of Cancer Survivorship,* including the subthemes, offer insight into the parental experiences and perceptions regarding the SCPs they receive. Understanding the *if, how,* and *why* SCPs are used by this population may help to determine alternatives for development and distribution of the SCP materials.

The results of this study offer many contributions to survivorship care that could potentially impact policy and procedures, and format, delivery, and educating with SCPs. Results related to accessibility of the SCP points towards the need to consider provision of an electronic SCP in addition to paper copies and verbal presentation of the information. Considering the model of survivorship care used became evident as a key factor in the provision of survivorship care services for survivors and their families. Further contributions of this study were manifested in the themes and subthemes related to the emotional impact of long-term follow-up care for survivors and their families. The significance of the long-term psychological effects suggests the need for further research directed specifically at support services and assessments for early recognition of these symptoms. Acknowledging the extensive impact cancer imparts on everyone involved calls for further evaluation of the current structure of childhood survivorship care, including support for the development and implementation of SCPs that offer flexibility to meet the needs of the survivor, the family, the healthcare providers, and the institution.

Summary of Recommendations

This study added to the overall knowledge of survivorship care with a focus on parental experiences with SCPs in managing their care of their child who has survived cancer. Recommendations arising from the findings of this study that may be of benefit to clinicians, educators, administrators and researchers who work in the area of pediatric cancer survivorship care include:

1. Consideration of a standardized yet flexible format of SCPs to offer healthcare professionals support in developing a SCP while allowing variability to suit the needs of the program and the survivor population.
2. Strategies and plans to empower healthcare professionals to feel confident in the delivery of SCPs and education of families and survivors in managing their ongoing healthcare needs.

3. Exploration of various formats for delivery of the contents of the SCP, including electronic access, information in other languages, and audio or visual formats. Consideration of educational level, individual learning needs and personal preference could be addressed to empower family and survivor participation in the survivorship care.
4. Attention to formal education of healthcare providers for the provision of pediatric oncology survivorship care with particular attention to managing the psychological and educational needs of the family and survivor.
5. Finally, the variability among survivorship care models currently operating poses advantages and disadvantages in the provision of services. Further study of what those implications are, and how they impact survivorship care for survivors and their families, is warranted.

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Appendix A

Research Ethics Approval - University of Alberta

UNIVERSITY OF ALBERTA

Research Ethics Office

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308 Campus Tower
Edmonton, Alberta, Canada, T6G 1K8
Tel: 780-492-0459
Fax: 780-492-9429
www.reo.ualberta.ca

Notification of Approval

Date:	October 09, 2014	
Study ID:	Pro00051914	
Principal Investigator:	Trina Adams	
Study Title:	Childhood Cancer Survivorship: A Qualitative Description of Parental Experiences with Survivorship Care Plans	
Approval Expiry Date:	October-08-15	
Approved Consent Form:	Approval Date 10/09/2014	Approved Document Consent Form

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

William Dunn, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix B

Research Ethics Approval - Athabasca University

Athabasca University
RESEARCH CENTRE

September 08, 2014

Miss. Trina Adams
Faculty of Health Disciplines
Athabasca University

File No: 21544

Certification Category: Human Ethics

Expiry Date: September 7, 2015

Dear Miss. Trina Adams,

The Faculty of Health Disciplines (FHD) Departmental Ethics Review Committee, acting under authority of the Athabasca University Research Ethics Board, to provide an expedited process of review for minimal risk student researcher projects, has reviewed you project, 'Childhood Cancer Survivorship: A Qualitative Description of Parental Experiences with Survivorship Care Plans'.

This was a beautifully done proposal on an interesting and important topic. Please make one addition to your Letter of Invitation; that is please just include the following sentence:

'This study has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this study, please contact the Office of Research Ethics at 1-800-788-9041, ext. 6718 or by e-mail to rebsec@athabascau.ca'

Your application has been **Approved on ethical grounds** and this memorandum constitutes a ***Certification of Ethics Approval***. You may begin the proposed research.

AUREB approval, dated September 8, 2014, is valid for one year less a day.

As you progress with the research, all requests for changes or modifications, renewals and serious adverse event reports must be reported to the Athabasca University Research Ethics Board via the Research Portal.

To continue your proposed research beyond September 7, 2015, you must submit a Renewal Request form before August 15, 2015.

When your research is concluded, you must submit a Final Report to close out REB approval monitoring efforts.

At any time, you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator at research_portal@athabascau.ca.

If you have any questions about the REB review & approval process, please contact the AUREB Office at (780) 675-6718 or rebsec@athabascau.ca.

Sincerely,
Sherri Melrose
Chair, Faculty of Health Disciplines (FHD) Departmental Research Ethics Board

Appendix C

Invitation Letter

My name is Trina and I am a Master of Nursing student at Athabasca University. I am interested in studying childhood cancer survivorship, particularly about how parents of survivors understand the packages they receive containing information about their child's cancer and treatment. This research project is a part of my thesis to complete my degree.

The packages you received are often referred to by experts in the field as *survivorship care plans*. The information in these packages can vary but generally include information on your child's cancer, treatments that were received (including chemotherapy, radiation and surgery), medications, risks for long-term effects and the need for follow up care.

I am looking to speak with parents of childhood cancer survivors who have finished treatment and have been enrolled in the Long-Term Survivorship Clinic program at the Stollery Children's Hospital. I am hoping to gain a greater understanding of how, or if, parents use the care plans in the care of their child. Understanding firsthand how the information is used by parents is important to the future of survivorship care. I have included a consent form with this letter which goes into more detail of the study. If you are interested in participating in my study please let your clinic nurse know and she will provide me with your contact information. Or if you would like more information, please contact me at (780) 634-5873 or adamsfarion@gmail.com

Thank you for your time,

Trina Adams

This study has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this study, please contact the Office of Research Ethics at 1-800-788-9041, ext. 6718 or by e-mail to rebsec@athabascau.ca

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Appendix D

Consent Form

Childhood Cancer Survivorship: Parental Perceptions of Survivorship Care Plans

Researcher	Thesis Supervisor
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This study has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this study, please contact the Office of Research Ethics at 1-800-788-9041, ext. 6718 or by e-mail to rebsec@athabascau.ca

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Information:

You are invited to participate in the following research study because you are the legal parental guardian of a child who has survived cancer and is currently enrolled in the long-term survivorship program at the Stollery Children's Hospital. You have received a *survivorship care plan* and are open to sharing your understanding and experiences with that information with me.

A *survivorship care plan* is made up of personalized information sheets developed by your oncology team to identify medical information related to diagnosis and treatments, possible late effects and recommended ongoing care. Some of the information you received would include education sheets about your child's cancer and reasons for ongoing tests. The function of the survivorship care plan is to act as a communication tool to allow parents to work with other care providers in caring for the needs of the cancer survivor. This promotes the parent and child understanding the cancer and its related risks and helping everyone to work together to ensure those risks are lessened or managed as the child ages.

Research Purpose:

The purpose of this study is to explore the experiences parents have had with survivorship care plans in managing the care of their child who has survived cancer. The study will focus on the perspectives of these parents as they have experienced survivorship care plans as tools to maximize the health outcomes and quality of life for their child. In addition to obtaining information about how the care plans are used, it is equally important to know if they are not used. This will help to understand how these care plans and the distribution of them can be reviewed and revised to meet the needs of all families and their child.

Research Description:

Parental guardians who voluntarily consent to participate in this study will engage in a telephone interview with the researcher. Interview questions will focus specifically on the survivorship care plan and the tools that you received in your package. The questions will aim to gather in-depth understanding of how you, as a parent, understand the package to assist in the care you provide to your child who has survived cancer. The interview will take approximately 15 minutes and will be audio taped with your permission. Any personal information or identifying details will be kept confidential.

Potential Benefits:

There are no direct benefits to your participation in this study. The results from this study may contribute to the knowledge related to survivorship care at the site and may be of future use to researchers or to the advancement of the survivorship program and/or care plans.

Potential Risks:

There are no anticipated risks in this study. Recollection of events and experiences that occurred during your child's treatment may cause an emotional response. The researcher will remain sensitive to the nature of the topic and will have additional resources available for support if desired.

Voluntary Participation:

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this site will continue and nothing will change. You can withdraw up to 30 days following your interview without any negative consequences by contacting the researcher via telephone or email.

Confidentiality:

All information collected during this study will be kept confidential. Audio tapes will be stored in a locked cabinet and will contain no identifying information. Data housed electronically will be stored on a password protected computer that will only be accessible to the researcher. The thesis supervisor will also have access to this information if required. A code will be assigned to your name, telephone number and/or email address for the purposes of communication with the researcher. The data will be destroyed after five years and final completion of the study and representation of the results.

Participant Consent:

If you have any questions related to this study, please contact the researcher or thesis supervisor via email.

I, ___________________________________, have read and understood the information in this letter pertaining to the research regarding childhood cancer survivorship care plans. I consent voluntarily to participate in the study, with the understanding that I am free to refuse to participate or withdraw from the study up to 30 days following the interview without penalty. I have had the opportunity to ask questions about the study and any questions I have been asked have been answered to my satisfaction.

________________________________	________________________________
Participant's Name (please print)	Participant's Signature and Date
________________________________	________________________________
Researcher's Name (please print)	Researcher's Signature and Date

Appendix E

Revised Research Ethics Approval - University of Alberta

UNIVERSITY OF ALBERTA

Research Ethics Office

308 Campus Tower
Edmonton, Alberta, Canada, T6G 1K8
Tel: 780-492-0459
Fax: 780-492-9429
www.reo.ualberta.ca

Notification of Approval - Amendment

Date:	March 09, 2015	
Amendment ID:	Pro00051914_AME2	
Principal Investigator:	Trina Adams	
Study ID:	Pro00051914	
Study Title:	Childhood Cancer Survivorship: A Qualitative Description of Parental Experiences with Survivorship Care Plans	
Approved Consent Form:	Approval Date 03/09/2015	Approved Document Consent Form - revised
Approval Expiry Date:	October-08-15	

Thank you for submitting an amendment request to the Research Ethics Board 1. This amendment to expand the study inclusion criteria, and to revise recruitment and interview methods has been reviewed and approved on behalf of the committee. The following have been approved:

- Invitation to Participate Letter - revised dated 01/12/2014
- Consent Form - revised dated 01/12/2014

Sincerely,

William Dunn, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix F

Revised Research Ethics Approval - Athabasca University

Athabasca University
RESEARCH CENTRE

December 01, 2014

Miss. Trina Adams
Faculty of Health Disciplines
Athabasca University

File No: 21544

Dear Miss. Trina Adams,

The Athabasca University Research Ethics Board has reviewed the modifications to your research entitled 'Childhood Cancer Survivorship: A Qualitative Description of Parental Experiences with Survivorship Care Plans' and confirms that the amendments you have outlined are approved.

You may proceed with your project as amended. Collegial remarks may accompany this review.

At any time you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator via research_portal@athabascau.ca.

If you have any questions about the REB review and approval process, please contact the AUREB Office at (780) 675-6718 or rebsec@athabascau.ca.

Sincerely,

Gail Leicht
Research Ethics Officer
Office of Research Ethics

Appendix G

Qualitative Content Analysis Process

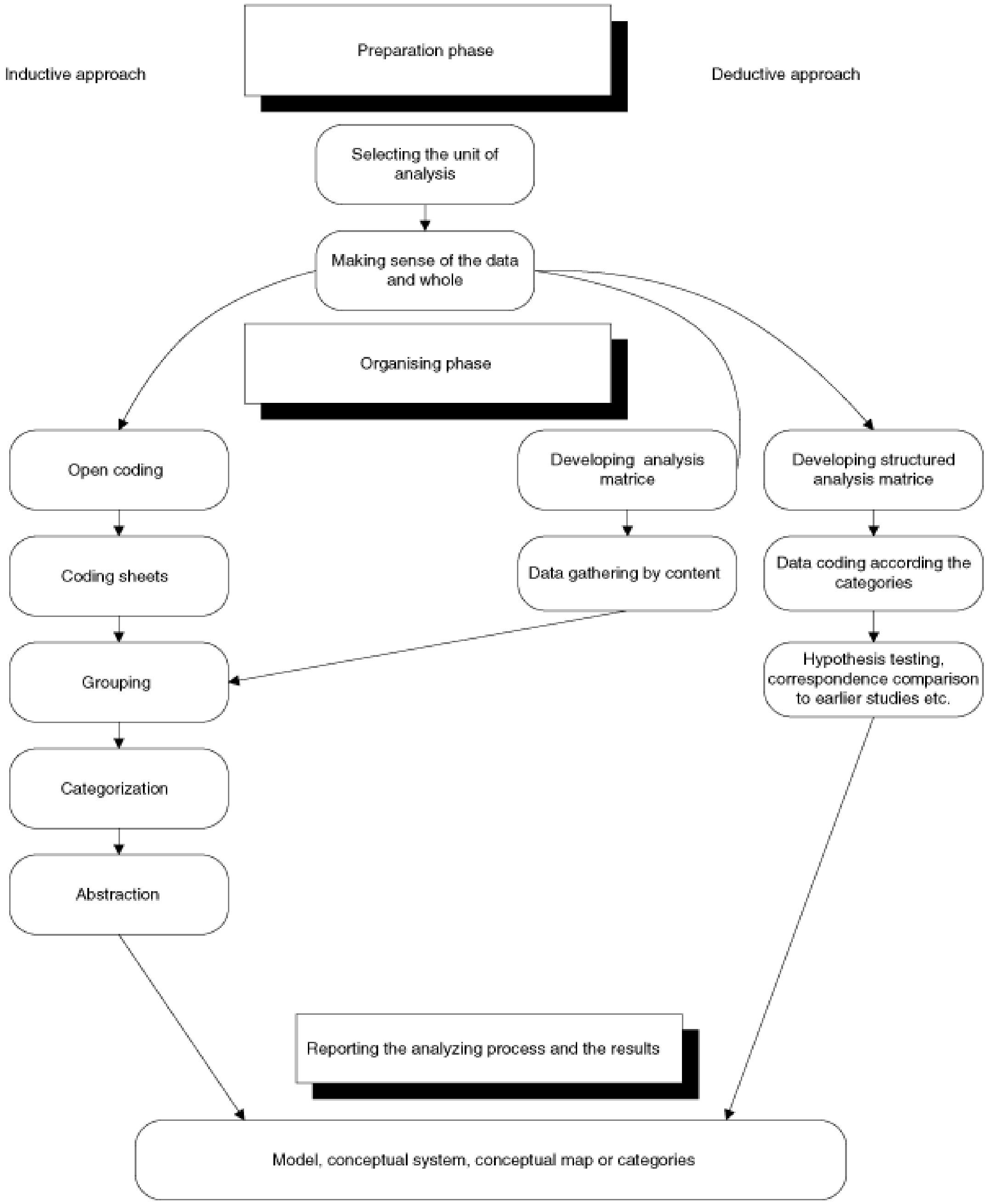

Figure 1. Preparation, organizing and resulting phases in the content analysis process. Adapted from "The Qualitative Content Analysis Process," by S. Elo and H. Kyngas, 2008, *Journal of Advanced Nuring*, *62*(1), p. 110. Copyright 2007 by Blackwell Publishing Ltd.