

**FACING THE UNKNOWN: EXPLORING THE IMPACT OF POSSIBLE INFERTILITY  
ON YOUNG ADULT CHILDHOOD CANCER SURVIVORS**

by

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## **Abstract**

**Background:** Approximately 83% of children diagnosed with cancer survive into adulthood.

Yet, adult survivors of childhood cancer (ACCS) are at high risks for late effects, conditions that develop 5 or more years following cancer treatment. Cancer treatments during childhood can cause infertility, a late effect associated with psychological distress and poor quality of life.

However, not all ACCS at risk for infertility have a definitive diagnosis and the experience of facing an unknown fertility status, and specific support needs of survivors remain poorly understood.

**Purpose:** The primary purpose of this research was to describe the challenges young ACCS experience when facing an unknown fertility status. This study also examined the ways in which men and women differed in their perceptions and experiences of unknown fertility.

**Methods:** This interpretive descriptive qualitative study included 10 ACCS, 5 men and 5 women, who participated in semi-structured interviews. Interview data were analyzed using an exploratory approach, allowing for content-driven inductive analysis, which involved open coding and constant comparative techniques to identify themes that captured the main similarities and differences in ACCS experiences.

**Results:** Six central themes emerged. First, living in the unknown is emotionally challenging for ACCS, in that the related fear, sadness and anxiety complicates the lives of the participants.

Second, possible infertility influences romantic relationships by impeding emotional connections and contributing to the worry of disappointing one's partner. Third, determining when to seek fertility testing is difficult, with readiness to have children and complications associated with fertility testing important considerations. Fourth, discussing fertility with health care providers, friends and family is awkward. Fifth, ACCS receive limited fertility-related education across the

cancer trajectory because of their young age at time of treatment and health care provider insufficient infertility-related knowledge. Lastly, ACCS perceive that fertility testing and confirmed infertility is detrimental to women but not men, which they attribute to both biological and gender differences.

**Conclusion:** This study provides beginning insights into the experiences of young ACCS as they navigate an unknown fertility status, and highlights existing gaps in fertility-related healthcare services.

## **Lay Summary**

Adult survivors of a childhood cancer are at risk for a large number of late effects from their cancer and cancer treatments. One late effect that adult survivors of a childhood cancer are at risk for is infertility. The purpose of this study was to explore the experiences of these individuals as they cope with an unknown fertility status, and to examine the differences in these experiences between men and women. By interviewing 10 participants, 5 men and 5 women, specific questions could be asked to explore how living with an unknown fertility status influenced the lives of the participants. It is hoped that the findings from this study can help lead to a better understanding of the challenges faced, and health care needs of adult childhood cancer survivors as they face possible infertility.

## **Preface**

This thesis is based on data from an original study conducted in collaboration with the primary supervisor, Dr. Fuchsia Howard, and supervisory committee members Dr. Sally Thorne and Dr. Karen Goddard. All parts of this thesis work were written by me, and then passed along to my supervisory committee for edits. None of the text of this thesis is taken from previously published manuscripts. The study was approved by the University of British Columbia Health Care Research Ethics Boards (REB) (certificate # H16-01916).

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## **List of Abbreviations**

ACCS	Adult Childhood Cancer Survivors
AYA	Adolescent and young adult
BC	British Columbia
BCCA	British Columbia Cancer Agency
COG	Children's Oncology Group
IGHG	International Guideline Harmonization Group
LEAF	Late Effects and Follow-up Clinic
PHSA	Provincial Health Services Authority
RT	Radiation Therapy
UBC	University of British Columbia

## Glossary

**Alkylating agents:** substance that causes replacement of hydrogen by an alkyl group especially in a biologically important molecule; specifically: one with mutagenic activity that inhibits cell division and growth and is used to treat some cancers.

**Germ cell:** a cell containing half the number of chromosomes of a somatic cell and able to unite with one from the opposite sex to form a new individual; a gamete.

**Hematopoietic stem cells:** stem cells that give rise to all the other blood cells

**In vitro fertilization:** a complex series of procedures used to treat fertility or genetic problems and assist with the conception of a child, including the retrieval of mature eggs from the female's ovaries to be fertilized by sperm in a lab. Then the fertilized egg (embryo) or eggs are implanted back into the uterus.

**Leukemia:** cancer of the body's blood-forming tissues, including the bone marrow and the lymphatic system.

**Lymphoma:** cancer of the lymphatic system, which includes the lymph nodes (lymph glands), spleen, thymus gland and bone marrow.

**Neuroblastomas:** cancer that develops from immature nerve cells found in several areas of the body.

**Oocytes:** a cell in an ovary that may undergo meiotic division to form an ovum.

**Para testicular rhabdomyosarcoma:** a rare tumor arising from the mesenchymal tissues of the spermatic cord, epididymis, testis and testicular tunics.

**Soft tissue sarcoma:** Soft tissue sarcoma is a type of cancer that begins in the soft tissues of the body, such as muscle, fat, blood vessels, nerves, tendons and the lining of joints.

**Spermatogenesis:** the production or development of mature spermatozoa.

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I am also extremely grateful to my committee members, Dr. Sally Thorne and Dr. Karen Goddard. Dr. Thorne's passion and knowledge for nursing science and methodology was truly contagious. Her expertise in Interpretive Description, the methodology applied in my thesis work, was instrumental in my work, and her attention to detail helped to ensure that my research was of top quality. Dr. Goddard's knowledge and experience regarding childhood cancer survivors was tremendously helpful, and her willingness to assist in participant recruitment despite her busy schedule was truly advantageous.

Special thanks are owed to my parents, who have supported me throughout years of growth and education, and to my boyfriend, Brandon, who was always there to offer me unyielding support and encouragement. I would also like to thank my fellow students in the UBC graduate studies nursing and public health program, as well as all the amazing professors I had the pleasure of working with throughout my studies.

Last, but not least, I am incredibly grateful for the contributions of the participants of this study. Discussing one's fertility is both personal and emotional, and divulging personal experiences and information with a stranger is no easy feat. This study would not have been possible without the cancer survivors that I was able to speak with, their willingness to answer difficult questions and their openness in sharing their experiences with me in my first major research project is something I will never forget.

## **Dedication**

I would like to dedicate my thesis work to my parents.

Firstly, I would like to dedicate this work to my mom, whose strength in a time of great change and uncertainty is a true inspiration, and whose belief in me has always made me feel as if I can achieve anything I set my mind to. Thank-you for always being there for me, and for being such a great role model for your daughters.

Secondly, I would like to dedicate my thesis work to my father, who was diagnosed with early onset frontal temporal dementia at the start of my entry into this Master's program. Although his health has seen tremendous decline throughout the time I spent writing my thesis, and he will never be able to read and comprehend this work to its full extent, I know that if he had the capacity to understand that he would be very proud. His love, loyalty and dedication to our family in his healthy years have shaped me into the person I am today have been an instrumental part of my success as a graduate student.

# **Chapter 1: Introduction**

## **1.1 Background**

Survival rates for childhood cancer patients have dramatically improved over recent years. Today, over 80% of children diagnosed with cancer survive into adulthood (Ward, DeSantis, Robbins, Kohler 2016). Although survival rates have improved, Adult Childhood Cancer Survivors [ACCS] are at risk for a large number of late effects from their cancer and cancer treatments. Late effects from cancer treatments are defined as conditions that continue to develop 5 or more years after a cancer diagnosis (Greenberg, 2016). ACCS have been found to be at a higher risk for a number of late effects, including endocrinopathy, pulmonary dysfunction, neurocognitive disorders, cardiovascular disease, hearing loss, and reproductive dysfunction (Hudson, Ness, Gurney, Mulrooney, Chemaitilly, Krull, Green, Armstrong, Nottage, Jones, Sklar, Srivastava, Robinson 2013).

In order to address late effects faced by ACCS, the British Columbia Cancer Agency [BCCA] and Provincial Health Services Authority [PHSA] has created a specialized program dedicated to caring for this patient demographic. A new clinic called the Late Effects, Assessment and Follow-up [LEAF] Clinic opened in July 2016 to ensure that ACCS continue to receive life-long, appropriate care. The LEAF clinic follows ACCS with medical assessment of physical and mental health and provides medical and psychosocial support. In addition, ACCS who have been lost to follow-up are seen in consultation and the clinic staff work with these individuals to understand the nature of their previous illness and treatment together with the related long-term health problems and risks. Guidance is provided regarding screening and much needed psychosocial support is provided.

Although the LEAF clinic has become an important source of survivorship care for ACCS, the availability and attainment of specialized fertility services, such as fertility counselling and reproductive medicine, is relatively unknown for this particular population. In Canada, the availability of in vitro fertilization [IVF] clinics varies from province to province, with the literature suggesting that the majority of adolescent and young adult [AYA] cancer patients fail to obtain fertility counselling even though maintaining options for fertility is expressed to be of primary importance (The Canadian Partnership Against Cancer, 2017). In addition, fertility clinics in Canada are projected to lack the capacity to care for the growing volume of ACCS and adolescent and young adult cancer patients that undergo cancer treatments and reach the survivorship stage. Although the data is not known for ACCS, if all women (aged 15–39 years) currently living with cancer were referred for fertility consultations (e.g., to discuss egg harvesting), fertility clinics could see an increase of 123 patients per clinic per year in BC alone. This increase would put a large amount of strain on the fertility clinics that are in place to serve all men and women in the province. Therefore, due to the unknown ability of the current provincial and national fertility service infrastructure to meet the needs of the ACCS population, research illuminating the attainability of this resource remains critical.

While working for Dr. Howard as a research assistant in the School of Nursing at UBC, I had the opportunity to be involved in research that focused on ACCS and their post-cancer experiences. This was my first experience partaking in research involving cancer survivors, as well as my first experience conducting qualitative data analysis. Not only was I exposed to rich descriptive data that highlighted the unique experiences of cancer survivors, but this opportunity was vital in providing me the chance to practice my thematic analysis techniques. After conducting a preliminary analysis of Dr. Fuchsia Howard's research data, inclusive of in-depth

interviews with 30 childhood cancer survivors, Dr. Howard and I recognized that fertility was a main concern for these cancer survivors even though examining fertility issues was not the primary study goal. We were able to identify three preliminary themes related to survivors' experience with uncertain fertility status, including: (1) anxiety related to potential infertility, (2) a strong influence on relationships with one's partner, and (3) worry about the health of their future children.

Although the initial data analysis of Dr. Howard's previous study provided evidence that both male and female survivors experience challenges when facing fertility issues, there was insufficient data from this study to conduct a full secondary data analysis because the study questions were not specifically designed to investigate fertility. Thus, a follow-up study was deemed appropriate, wherein questions could be tailored to specifically explore fertility-related concerns that would garner more descriptive and in-depth data. After reflecting on the themes apparent in Dr. Howard's previous study, and the recommendations for further research made by other studies identified in the literature review, pertinent research questions designed to specifically explore fertility issues in ACCS were created to form this preliminary exploratory study.

## **1.2 Purpose**

The purpose of this study, titled "Facing the Unknown: Exploring the Impact of Possible Infertility on Young Adult Childhood Cancer Survivors", was to illuminate the experiences and identify possible challenges that ACCS experience in relation to having an unknown fertility status. By examining the issue of unknown fertility through a gendered lens this study was able to explore the unique experiences of men and women who have survived childhood cancer by investigating the ways in which gender norms, relations and expectations shape individuals'



perceptions and experiences with fertility issues. Gender is defined as the socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women (World Health Organization [WHO], 2017). Along with gender, sex was also examined, as the actual physical differences in males and females have a large influence on the processes of determining fertility status. Sex is defined as the biological and physiological characteristics that define men and women (WHO, 2017).

The experiences and possible unmet needs identified from the interviews are intended to help guide better health care service, and form the basis of an information sheet for ACCS. The information sheet for ACCS will be placed at the LEAF Clinic in Vancouver, BC, and will supply critical information regarding fertility to ACCS that may be missed by health care providers, alleviate common fears and misconceptions regarding possible infertility, and offer survivors valuable knowledge of fertility resources available in British Columbia.

### **1.3 Treatments Causing Fertility Issues & National Guidelines**

A review was done to identify cancer treatments that are known to be associated with fertility problems, as well as current recommendations for practice, to provide further context as to which ACCS may be concerned about their fertility status, and how medical practitioners are being guided when caring for these individuals.

#### *Cancer Treatments & Infertility*

The most common types of cancer in Canadian pediatric patients include: leukemias (32%), CNS tumours (19%), lymphomas (11%), neuroblastomas (8%), and soft tissue sarcomas (6%) (Statistics Canada, 2014). For the majority of pediatric cancers, treatment is multimodal and includes various combinations of chemotherapy, radiation therapy, surgery, and in some instances hematopoietic stem cell transplantation (Antal & Sklar, 2015). Male and female

infertility and hypogonadism (diminished functional activity of the gonads—the testes in males or the ovaries in females) are common complications resulting from these treatments (Mead, 2007). In males, chemotherapy can damage spermatogenesis both temporarily or permanently, with the degree of gonadal stem cell damage fluctuating according to the drugs used, dose of the drug administered, the route of administration, and whether combination therapies were given. It is well documented that alkylating agents are the most toxic chemotherapy drugs as their use can lead to permanent absence of viable sperms (azoospermia). In terms of radiation, testes directly irradiated in the treatment of tumours of the lower pelvis, leukemic relapse, testicular tumors (such as paratesticular rhabdomyosarcoma and germ cell tumors), as well as total body irradiation (TBI) with high-dose chemotherapy, can lead to sterilization.

For females, the ovary is chemo-sensitive. Due to the fact that women are born with a finite number of oocytes that naturally decline over time, cancer treatment at an older age, even within the pediatric age group, results in a higher risk for reduced fertility due to a decreased ovarian reserve (Antal & Sklar, 2015). Chemotherapy can further result in loss of primordial and growing follicles, with a consequential loss of hormone production, cease in menstruation, and the potential for early menopause. Ovarian toxicity varies depending on the regimen of chemotherapy given, therefore the result may range from no effect to permanent ovarian failure (Mead, 2007). As in males, alkylating agents are more damaging to the ovary than other agents, however there is limited data quantifying the extent of ovarian damage from these drugs. Radiation procedures produce severe dose-related gonadal damage to the germ cell and endocrine components of ovarian tissue and can result in immediate permanent sterility, temporary cessation of menses and premature menopause. Along with ovarian tissue, uterine tissue can also be damaged by radiation treatments, and may be affected in treatment of the

pelvic lymph nodes, rectal cancer or sarcomas of the pelvic side walls, gynaecological tumours, anal and central pelvic sarcomas. Just as in males, TBI in females has been shown to likely result in infertility, and early menopause secondary to ovarian damage (Schimmer, Quatermain, Imrie, 1998).

In both male and female children with cancer, radiation to the hypothalamic–pituitary axis may also produce deficiencies in gonadotrophin production (Antal & Sklar, 2015). This will present as amenorrhea/hypogonadotrophic hypogonadism many years later and is more likely to occur when pituitary reserve is already diminished after pituitary tumour surgery has been done. Radiation doses of 45 units of gray (Gy) in adults, and even less in children (24–35 Gy) carry high risk of gonadotrophin deficiency. Doses that pose significant risk may be administered in prophylaxis for brain tumours, tumours of the orbit and paranasal sinuses. The risk of infertility related to the surgical removal of malignant cells in both males and females is directly relevant to the site of tumour and whether reproductive tissue of the reproductive system is involved. In males, surgeries for tumors involving the testes, prostate, bladder and colon can lead to possible infertility (American Cancer Society, 2017). In females, surgery may involve removal of any part or all of the reproductive organs, including the uterus (hysterectomy), cervix (trachelectomy or hysterectomy), one or both ovaries (oophorectomy), as well as surgery to remove pelvic lymph nodes, may negatively influence fertility (Journal of Clinical Oncology, 2016).

In order to gain a sense of the risk of infertility in ACCS, researchers have examined the rates of infertility in those who have had a childhood cancer versus those who have not using sibling controls. Data from a subset of patients in the Childhood Cancer Survivor Study cohort, which compared rates of pregnancy and live-births between childhood cancer survivors and their siblings, was recently evaluated (Chow E, Stratton K, Leisenring W. et al., 2016). The study

included data following patients (n= 10, 938) diagnosed and treated for the most common types of childhood cancer, and their siblings (n = 3949) across the United States and Canada between 1970 and 1999. Findings showed that male survivors had a 37% decreased likelihood of both pregnancy and live-births compared to their siblings, while females had a 13% decrease in the likelihood of pregnancy and a 18% decrease of live-births compared to their siblings.

### *Current Recommendations*

The need for structured, multi- disciplinary and evidence-based long-term care plans for ACCS is well articulated in a recent European survey of experts, however it is noted that few countries in the world actually have specific national guidelines. Even fewer have follow-up care guidelines specifically tailored to outline practice recommendations regarding fertility and other late effects experienced by cancer survivors. The Children's Oncology Group (COG), a clinical trials group supported by the National Cancer Institute (NCI), is the largest organization dedicated solely to pediatric cancer research. The vast majority of centres that treat childhood cancer in the US, Canada, Australia and New Zealand are part of the COG. The COG endorsed the "Fertility Preservation for Patients with Cancer" guideline in December 2014, for which revisions were made in December 2016. This guideline offers a general guideline for practice, including key points on provider and patient communication and the role of the health care provider in advising patients about fertility preservation. It was also noted in this guideline that patients should be referred to reproductive specialist, mental health specialists and advocacy organizations as needed. Although European centers are not part of the COG, they have collaborated with the COG to develop internationally accepted guidelines for ACCS follow-up care, through the formation of a group called the International Guideline Harmonization Group (IGHG) for Late Effects of Childhood Cancer. The IGHG is described as a worldwide endeavor

initiated by several national guideline groups and the Cochrane Childhood Cancer Group in partnership with the PanCareSurFup Consortium to collaborate in guideline development. The primary goal of the IGHG is to “establish a common vision and integrated strategy for the surveillance of chronic health problems and subsequent cancers in childhood, adolescent, and young adult cancer survivors” (IGHG, 2017).

New Zealand also has its own guideline to assist practitioners, titled “Fertility Preservation for People with Cancer: A New Zealand Guideline”, which was developed in 2014. This guideline provides information pertaining to fertility discussion, managing the fertility preservation process, options for fertility preservation, and long-term follow-up. The overarching purpose of this guideline is to provide information for health professionals about risks to male and female fertility associated with cancer treatments, information about current methods of fertility preservation and how these methods can be accessed, and recommendations for monitoring the reproductive ability of cancer survivors’ post-treatment. Two separate fertility preservation algorithms, for both females and males, are included in this document to help care providers offer cancer patients the best resources and options to maintain fertility. This guideline also contained a clear section designated to long term follow up, in which it is noted that there is limited high level evidence on which to base recommendations for long term follow-up after cancer treatment.

Further useful clinical practice guidelines have been recommended in Switzerland, in the publication titled “Cancer, pregnancy and fertility: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up”. This guideline was created by the European Society for Medical Oncology in 2013, and was further endorsed by the Japanese Society of Medical Oncology. This guideline discusses various cancers and treatments that can alter an individual’s

reproductive ability, cancer during pregnancy, managing pregnancies diagnosed while undergoing anticancer therapy, and pregnancy in cancer survivors. The fertility preservation methods recommended for male and female cancer patients are similar to the COG recommendations however it is interesting to note that only reproductive counseling is recommended for females. This tool is primarily focused on preserving fertility in cancer patients while they undergo treatment, and does not offer much information that can guide follow-up care for those that have survived cancer.

Lastly, the Sociedad Española de Oncología Médica (SEOM) Clinical Guideline of fertility preservation and reproduction in cancer patients (2016) was examined. This clinical guide was developed in Spain, in response to the identified need for improvements in clinical care to ensure patients are well informed about infertility risks and fertility preservation options and to support them in their reproductive decision-making prior to cancer treatment. In this particular guideline, cancer treatments were clearly organized in low, medium and high-risk categories, and it provided 2 options for fertility preservation in males, and 5 options for fertility preservation in females. Much like the tool developed in Switzerland, this clinical guideline was primarily designed to guide care for patients undergoing cancer treatments, and offers little information regarding care that should be offered to cancer survivors once they are past the treatment phase.

## **1.4 Chapter Summary**

This chapter provided important background information regarding fertility as an issue in cancer survivorship, outlined the purpose of this study, and provided a summary of the current recommendations for practice. Multiple resource tools were found which were designed to assist health care practitioners in reducing the negative impact of late-effects in ACCS. These tools

clearly identify which cancer treatments can cause infertility, and were able to make clear recommendations as to how fertility should be preserved in males and females. The recommendations for fertility preservation in both sexes were constant across all guidelines. The recommendations related to follow-up care and long-term surveillance of fertility problems in cancer survivors were, however, varied between documents, as some explicitly mentioned follow-up care, while some did not.

## **Chapter 2: Literature Review**

### **2.1 Introduction**

A literature review was completed in order to examine previously conducted studies that investigate fertility issues in cancer survivors. Thirty-four previous studies were reviewed in detail to explore the current state of the literature examining cancer survivors' challenges facing fertility issues. These studies were published between 1999 - 2017 in a variety of different countries, including the United States, the United Kingdom, Sweden, Australia, Germany, Belgium, Holland, Canada, Hungary, and Korea. Out of all of the studies reviewed, 25 studies focused on both men and women, 5 studies focused only on women, 3 studies focused only on men and 1 study focused on Lesbian Gay Bisexual Transgender and Queer individuals (Appendix A). Analyzing the identified studies led to the identification of 6 key themes found to be prevalent in the literature, including; fertility as a priority for ACCS, the impact of fertility issues on health, unmet needs regarding fertility, the influence of sex and gender on the experience of possible infertility, the need for further research and changes warranted in current practice. These themes will be elaborated upon to demonstrate what is currently known regarding the late effect of infertility in ACCS, and to provide an overview of current recommendations for health care providers.

### **2.2 Fertility: A Priority for Young ACCS**

One overarching theme evident in the literature is that fertility is a priority for ACCS, who consistently rate the inability to conceive as one of the most detrimental late-effects. Most recently, a study published in 2017 by The Canadian Partnership Against Cancer found that both male and female adolescent and young adult (AYA) cancer patients identified fertility as a primary concern, and that the emotional and financial impact of the inability to become



biological parents can be devastating to individuals and their families (The Canadian Partnership Against Cancer, 2017). In a study by Klosky and colleagues, (2015) “having children” was ranked as a top 3 life goal among 43.8% of adolescents who had been treated for a pediatric cancer, with fertility concerns ranked higher than concerns related to home ownership and wealth. In another study by Thompson, Long, and Marsland (2013), worries about fertility and the health of future children was one of the 4 most prevalent themes. Research has also shown that experiencing cancer places an additional emphasis on family closeness and parent-child relationships, possibly magnifying the importance of conceiving (Knopman, Papadopoulos, Grifo, Fino, Noyes, 2010).

Research by Stein and colleagues (2014), who conducted focus groups with 15 male survivors of pediatric cancer, provides further evidence illuminating the importance that ACCS place on fertility preservation. The theme most frequently expressed by these ACCS was regret and a retrospective desire for improved reproductive health and fertility preservation education. In this study, 24% of childless male cancer survivors reported that their cancer experiences increased their desire to have children. When Yi, Kim and Sang (2015) conducted a similar study utilizing qualitative interviews, survivors' worries were identified in five themes, the first being romantic relationships and marriage, and the second being fertility and the health of future children. The themes of work and social life, family, and physical health came next. Another notable finding in this study was that most of the 15 male and 13 female participants reported that they were fearful of their future children also being inflicted with cancer.

### **2.3 The Impact of Fertility Issues on Health**

The literature suggests that fertility issues have a strong relationship with health and wellbeing, with possible or confirmed infertility correlated with poor mental health outcomes

and quality of life, as well as increased loneliness and depression. A study conducted by Armaund, Wettergren, Rodriguez-Wallberg & Lampic, (2014) found that, among survivors with a pretreatment desire to have children, those who had been able to have children after cancer rated their mental health (as measured by the Mental Component Summary scale) as better than those who had not had any children. These researchers concluded that an unfulfilled desire to have children was significantly associated with poorer mental health outcomes. These study findings were mirrored by Yi et al. (2015), who found that survivors reported worrying significantly more about fertility in contrast to their healthy peers, and that ACCS who were experiencing reproductive concerns had a much stronger correlation to moderate to severe depression.

Along with increased worry and depression, ACCS also experience increased loneliness. In a study inclusive of 21 female and 7 male cancer patients, loneliness was a central theme in the experience of potential fertility loss. This loneliness was reported to be a result from communication difficulties between the patient and health care providers, or members of his or her social environment (Goosens, Delbaere, Beeckman, Verhaeghe, & an Hecke, 2015). The researchers discovered that even those who reported a high level of support from friends and family throughout their cancer treatment expressed feeling alone and internally conflicted. This study also revealed that the high sensitivity of the issue, feelings of being different from peers, inability of family members and others to understand the experiences of participants, lack of public knowledge that infertility can be a side effect of cancer treatment, and a sense of being judged all contributed to communication difficulties thus resulting in internalization of fertility related problems and a higher level of mental health issues.

For many cancer survivors, not only did fertility issues affect reproductive function and loneliness, but it also influenced identity, well-being and life planning (Crawshaw, 2010). In a study by Ellis, Wakefield, McLoone, Robertson, & Cohn (2016) uncertainty regarding fertility outcomes was associated with emotional distress in 24 out of 38 parents and 3 out of 7 survivors. Some families in this research reported a high level of anticipatory grief regarding potential fertility loss and that the consistent bad news regarding both cancer and fertility contributed to negative health outcomes. Additionally, potential or perceived infertility was linked to lower self-esteem, confidence, and body image, which the researchers point out have a negative impact on the development of interpersonal and romantic relationships and life satisfaction.

In an alternate study, done by Gorman et al (2013), which aimed to develop a reliable and valid scale to measure the reproductive concerns of young adult women ACCS, the survivors had substantial concerns regarding fertility and parenthood issues that extended beyond biologic fertility potential. In total, 229 female ACCS completed this survey, and those with higher levels of reproductive concerns, reported statistically significant higher rates of depression and lower quality of life. Along with the previously mentioned health implications regarding possible infertility, ACCS also reported nervousness and apprehension about their ability to be a good parent (Langeveld et al., 2004). In fact, one study found that feeling healthy enough to be a suitable parent after cancer was the strongest predictor of emotional well-being (Schover, Rybicki, Martin, & Bringelsen, 2002). Interestingly, a key finding from interviews with 25 survivors, 19 of whom were women, was that individuals who already had children and/or who did not desire to have children in the future were also distraught by potential infertility (Penrose et al., 2011). The researchers thus hypothesized that there is a strong correlation between fertility and self-concept among ACCS.

## **2.4 Unmet Needs Regarding Fertility**

Although the literature indicates that fertility is a primary concern for cancer survivors and that these concerns can have a negative impact on health outcomes, ACCS often report that their learning and care needs related to fertility are unmet. Studies have shown that a large number of ACCS do not receive adequate information regarding fertility preservation at the time of diagnosis, nor do they receive follow-up information regarding fertility post-cancer treatments. In a survey of 283 ACCS (43 men and 89 women), only 57% received information from their health care providers about infertility after cancer (Schover et al., 1999). In research involving testicular cancer survivors, the most common solid-tumour cancer in males aged 15-29 (Carpentier & Fortenberry 2010), it was reported that survivors experienced significant regret that their fertility might have been unnecessarily damaged due to limited knowledge of fertility-preservation treatments. Although not all survivors that were included in this study were ACCS, adolescent and young adult survivors (AYA) may have similar experiences.

Receiving insufficient information regarding decision-making and fertility was also identified as a theme in a study involving 25 AYA cancer survivors under the age of 50, wherein respondents reported perceiving their medical care providers to be ineffective in fertility counselling, as they often failed to address fertility at diagnosis which consequently impacted the decision-making process (Penrose, Beatty, Mattiske & Koczwar, 2011). In this study, the study participants recommended that more information and support services be offered to cancer survivors specific to fertility preservation. In an alternate study, involving 56 female ACCSs, and a high rate of education beyond high school, only 32% had sufficient knowledge of their potential reproductive issues, and only 9 (5%) of these women had reproductive counselling before or after their cancer treatments (Kim & Merseeau, 2015). Survivors and their parents

reported that the issue of fertility preservation was not raised by their primary physician before or during cancer treatments, which they described as being detrimental because their providers were their primary source of information. When focusing on male ACCS, Stein et al. (2014), reported that although future reproductive potential was not necessarily a primary concern at the time of cancer diagnosis, it was a principal concern later in life and participants found their primary physician to lack attention to this issue. Furthermore, the majority of men in this study wished they had been connected with a fertility specialist and were never presented with this opportunity or educated as to how connecting with a fertility specialist could be helpful.

## **2.5 Influence of Sex and Gender**

Another highly prevalent theme in the literature was the differences reported in fertility related experiences based on sex and gender. In terms of sex, it is known that fertility preservation options vary drastically between males and females (Knopman, 2010). For males, sperm banking is a clinically established method to preserve a patient's future reproductive ability, and is uncomplicated, affordable, and usually does not cause treatment delays. For females, however, fertility preservation is costlier and time consuming, and entails ovarian stimulation and cryopreservation of embryos or mature oocytes, which can take 2-6 weeks. While the cost for fertility evaluation for men, via a semen analysis, is offered for roughly \$100.00 to \$250.00 in Canada, the cost for women's fertility evaluation is much greater. Initial female fertility evaluation can include ovarian reserve testing including an evaluation of the FSH (follicle-stimulating hormone) on the 3<sup>rd</sup> day of a woman's menstrual cycle and an antral follicle count done via vaginal ultrasound examination. Based on the results from these initial evaluation techniques, further tests are needed, such as a clomiphene citrate test, hysterosalpingogram (HSG) evaluation through a diagnostic x-ray that allows a study of your

uterus and fallopian tubes, hysteroscopy, and an evaluation of prolactin, thyroid stimulating hormone (TSH), VZV IgG (to test chicken pox exposure), rubella titre, complete blood count, blood type, and HIV, hepatitis B, hepatitis C, syphilis testing may be done. The procedure for females also requires hormonal therapy for which negative effects, such as an increase in breast cancer rates, have been questioned (Armaund et al., 2012). Just like fertility preservation, the actual process of determining ones' fertility status is also much more burdensome for females, as compared to a sperm analyses that men undergo, women must have tubal evaluation and ovarian reserve testing; both of which are invasive procedures.

The literature suggests there are differences in the degree to which fertility preservation is discussed and offered to males and females prior to cancer treatment initiation. In the study by Armaund et al. (2012), it was found that among male participants, 54% used fertility preservation options, while only 2% of females used fertility preservation options. Furthermore, the majority of men had fertility related discussions with their care providers, while only half of the women in the study recalled fertility being mentioned. Female ACCS have also reported more cancer-specific concerns than male survivors in adulthood (Langefeld et al., 2004). The difference between female and male ACCS was recurrent, as in an alternate study, the information that was given to cancer survivors varied significantly by sex. This study, by Armuand et al (2012), found that the majority of male participants reported that they received information about treatment impact on fertility (80%) as well as fertility preservation (68%), while less than half of female survivors (48%) reported that they had received information regarding their treatment impacts on fertility, and even fewer reported receiving information about fertility preservation (14%).

Although the impact of biological sex is evident in relation to fertility procedures, differences in fertility-related distress between men and women have led researchers to question whether gender-role socialization might be a better predictor. Gender-role socialization refers to the theory that, although biology plays a part in gender, differences between the sexes are a product of learning that is transmitted across generations and reinforced by society (Pikler & Brown, 2010). According to Pikler and Brown (2010), gender-role socialization may be more significant than sex in the development of depressive symptoms among cancer survivors and their romantic partners. The authors identify that the undifferentiated gender-role orientation remains an under- studied gender identity, and that, because those who subscribed to an undifferentiated gender role have been found to be at a heightened risk for depressive symptoms, future research focusing on gender and fertility-related health is needed. In a study by Russell, Galvin, Harper and Clayman (2016), who conducted semi-structured telephone interviews with LGBTQ (n = 22) and heterosexual (n = 34) survivors, heterosexual survivors reported fertility concerns as affecting romantic relationships more often ( $p < .05$ ) than their homosexual counterparts. LGBTQ survivors were also more willing to raise non-biological children or to not become a parent in comparison to the heterosexual survivors in the study.

Gender stereotyping and the notion that many men are raised with the ‘boys don’t cry’ doctrine, might lead men to be more reserved about their health problems in comparison to women, who may be more willing to articulate symptoms (Langeveld, 2004). This could be tied to study findings indicating that men perceive their quality of life as being better, had higher mean self-esteem scores, and worried less than the women. According to Moynihan (2002), a gendered analysis using a qualitative approach holds potential for revealing the ways in which sexuality is provisional to time and place. Additionally, Moynihan reasons that in the

psychosocial cancer literature, the nature of loss is accompanied by the necessary emotion of grief, which is characterized by a range of emotional expression guided by gender norms.

## **2.6 The Need for Further Research**

A highly prevalent theme found in the literature was the identified need for future research to guide better care for cancer patients both during their cancer treatments and throughout survivorship. Further studies were recommended to address a variety of understudied phenomena, including quality of life in ACCS, social functioning of ACCS, ACCS attitudes towards and experiences with fertility, the benefits of reproductive counselling for ACCS, and the influence of gender on survivorship after cancer. The need for qualitative studies to illuminate patient experiences was a common subject in the authors' recommendations.

Quality of life, and how cancer survivors are able to live and cope with their altered lives after cancer was expressed as an area that needed more attention by multiple authors. Langeveld, Grootenhuis, Voute, De Haan and Van Den Bos (2004) stated that further research exploring determinants and indices of quality of life and worries in long term survivors is warranted. According to Carpentier et al. (2010), sexual function, fertility and body image represent additional targets to assess survivors' quality of life, and that all of these must be explored in greater depth. In particular, further qualitative research is recommended that explores, in survivors' own words, the effect of cancer on such areas. Thompson et al (2013) further indicated that qualitative methods, using techniques such as open-ended interviews, have the ability to play an important role in guiding new measures to more accurately evaluate social functioning of ACCS.

Schover et al. (1999) described the need for research that explores in-depth the difficult choices that cancer survivors must make about having children, specifically including the impact



of age at cancer diagnosis on attitudes regarding fertility and having children, and the degree to which conservative treatments that preserve fertility influence overall quality of life and patient satisfaction. Future studies recommended by Kim et al. (2015) include expanding to larger study populations and tailoring reproductive counselling or educational material to meet the needs of ACCS. These authors also recommend that research incorporating reproductive counselling into routine follow-up care would provide evidence of how best to meet ACCS educational needs.

In terms of gender research, Moynihan (2002) made the claim that women with cancer are pathologized and medicalized, while men with cancer are under-researched. The need for future research, especially in regard to the influence of gender, is articulated, with hopes that findings from future studies can pave the way for a clearer understanding of how patients experience both cancer and cancer survivorship. Cserepes, Kollar, Sapy, Wischmann and Bugan (2013) recommended that for further research, qualitative methods should be used to discover the proper conception regarding gender roles and how this may influence the value of a child in society. Future international studies that involve both social and personal factors would also offer important insights.

## **2.7 Identified Practice Changes**

The need for future practice change was a theme that came hand-in-hand with the identified need for future research, as recent findings continue to warrant changes in service delivery regarding ACCS fertility needs. In one study, that sought to understand how young female cancer survivors feel about fertility and parenthood (Gorman et al., 2012), young survivors felt they could benefit from improved information in relation to their fertility and parenthood options in the survivorship phase. The authors conveyed that, along with better provision of fertility related information, enhanced coordination of medical care and increased

support in navigating emotional issues related to reproductive problems would improve care offered to ACCS. Understanding these concerns through research is noted as a first step towards creating successful interventions that are targeted to the needs of young ACCS who wish to become parents. In another study, 18 of 38 parents and 3 of 7 ACCS identified challenges in communicating with health care providers (Ellis et al., 2016). Patients reported being uninformed of potential problems regarding fertility, and that despite wanting to know, they were also confused about their fertility testing options.

Despite the strong desire of many cancer patients to sustain their fertility, several factors obstruct the initiation of fertility preservation discussion with health care practitioners. In a survey of oncologists in the United States, knowledge of resources, practice behaviors, perceptions of patient characteristics, and quality of discussion were identified as barriers in conversing about fertility preservation. Therefore, another practice change recommendation was to include better education for health care professionals regarding fertility issues in cancer survivorship. In a study conducted by Nilsson et al (2014), researchers investigated what adolescent and young adult childhood cancer survivors thought about their risk of being infertile and how they felt about their ability to have biological children. This study recommended that health care professionals systematically address fertility issues and future parenthood and that communication should improve by providing more information and better support. In the study done by Armuand et al (2014), findings stress the importance of discussing fertility-related aspects of family planning with patients who have no expressed desire for children, particularly those of young age and who have not had children, as these views and desires can change throughout the life-course.

Apart from the need for increased communication between health care providers and ACCS, a further recommendation was to improve the delivery of these services. The recommendation that fertility-related care for ACCS must be multi-disciplinary was common throughout the majority of the literature. It was expressed by Knopman et al. (2010) that a dedicated multidisciplinary team consisting of medical or surgical oncologists, a reproductive endocrinologist, a genetic counsellor, perinatologist, and psychologist is highly recommended. The authors identified oncologists' knowledge of resources, practice behaviours, and perceptions of patient characteristics to be potential barriers to adequate care, and proper training to be a priority for these professionals. Although reproductive counselling is widely known to be a vital component of pre-treatment and post-treatment work up, few patients actually receive these services (Jido & Cruickshank 2015). By encouraging multi-disciplinary care teams to address fertility issues for ACCS, and increasing care provider's training and awareness regarding resources that should be made available to ACCS, it is hoped that more holistic, comprehensive care plans can be developed.

## **2.8 Chapter Summary**

This chapter illustrates that although current literature suggests fertility preservation as being a priority for ACCS, there are often many unmet needs experienced by ACCS in regard to this particular late effect. These unmet needs are due to a lack of communication with service providers, leading to ACCS possessing insufficient knowledge of their own fertility status and available resources and facing uncoordinated specialist services. The accessibility of fertility resources for ACCS remains unknown in BC, and any barriers that exist in obtaining fertility support, including counselling, education, and treatment, requires further investigation. Although researchers have begun to describe how sex or gender may impact the experience of infertility

after cancer, little remains known in this area, and more research has been recommended. Further qualitative studies, which seek the opinions and experiences of cancer survivors themselves, will guide patient-centered practice and ensure that the long-term care offered to ACCS reflects their needs.

## **Chapter 3: Methods**

### **3.1 Research Questions**

To address current knowledge gaps, pursue areas of research recommended by previous studies, and build upon recent findings, three research questions were formed.

The primary research question is:

- (1) What challenges do young ACCS experience when facing unknown fertility status?

The secondary research questions are:

- (2) In what ways might experiences of unknown fertility status differ in male and female ACCS? And,
- (3) How do young ACCS interpret and communicate their information and support needs in relation to their reproductive health?

### **3.2 Interpretive Description**

The methodology utilized in this study was interpretive description [ID]. ID is a credible methodology in qualitative health research that can be applied to assist the researcher in generating better understandings of complicated experiential clinical phenomena (Thorne, 2008). The participants for this study were recruited through a convenience sample, where individuals who fit the inclusion criteria were invited to participate (Polit & Beck, 2012). This recruitment strategy ensured that participants could speak to the phenomenon under study, and that the specified research questions could be appropriately answered. The data collection was done using individual, semi-structured interviews containing open-ended questions to elicit detailed, personalized responses from each participant. In this chapter, the way in which ID was utilized to enhance data collection and data analysis will be described.

ID was used to assist the researcher in gaining insight into the complex issue of young ACCS's experience with possible infertility from within the context of nursing care. The justification behind choosing this specific research method was based on the desire to ensure that the complex nature of fertility issues could be thoroughly examined, and that the study's findings had adequate disciplinary relevance. While ID suggests that there is inherent value in systematic topic analysis, it also allows for the analysis to be placed back into the context of practice to ensure "real-world" applicability (Thorne, 2008). By exploring the experiences and views of young adult survivors of a childhood cancer living with the possibility of being infertile, valuable insight was gained to inform nurses, and other health care professionals, how care can be improved for this patient group.

Further, in accordance with ID, interviews were conducted with a heightened sensitivity to nuances of communication, such as subtle expressions of concern or other body language cues or pauses over the telephone that might help to identify issues regarding possible infertility that might garner further attention (Thorne, 2008). This data was gathered by taking field notes after each interview, and thoughtfully reflecting on it in conjunction with the thematic analysis that occurred with the transcribed dialogue. In doing so, interpretive description allowed for the capitalization on the idea that surface answers can be naturally misleading, and promoted the creative ability to explore the complexities of human experience (Thorne, 2016). Surface answers and initial responses drawn from interview participants often required careful speculation and further discussion so that the participant was enabled to share deeper layers of their thoughts and feelings, offering the researchers a more robust understanding of their experiences. Thus, participants were regularly asked throughout the interview process to explain their answers and provide examples from their experiences. In summary, ID served as a

comprehensive method of gathering and analyzing data and allowed for the construction of valuable, applicable findings that can build upon prior knowledge.

### *3.2.1 Study Setting*

Participants were offered the option to complete their interview either in-person at a location of their choice, or over the telephone. The in-person interviews were most often conducted in a public space, such as a café, with discretion paid toward ensuring confidentiality was appropriately maintained. A total of 3 interviews were conducted in-person, while 7 were conducted over the telephone. All interviews were conducted at a date and time chosen by the participant.

### *3.2.2 Study Participants*

A convenience sample of individuals, aged 19 – 36 years old who had survived a childhood cancer were included in this study. Further inclusion criteria mandated that each participant be a resident of BC, be currently living with an unknown fertility status, have no cancer treatments within the last two years, and understand and communicate in English. Recruitment was conducted through the BC Cancer Agency LEAF clinic located in Vancouver. Initially, patients seen by Dr. Karen Goddard, the medical director at the LEAF clinic, were provided with the study information through the form of a study poster. This study poster included a telephone number and email so that interested participants could contact a member of the research team should they wish to become involved. This resulted in a slow recruitment process, as despite best intentions, participants who originally expressed interest in participating while seeing Dr. Goddard often neglected to get in touch with the researchers. After 5 weeks of recruiting, the research team was only successful in gaining 2 study participants. This led to the altering of the recruitment strategy so that those identified by Dr. Goddard as wanting to

participate in the study could sign a new consent form (Appendix B) to being contacted by a member of the study team right away. After gaining an ethics amendment for this new recruitment method it was implemented at the LEAF clinic. This recruitment method proved to be much more effective, as the contact information of the interested participants could be gathered and researchers could immediately make contact to provide further study information, answer potential participant's questions and validate interest. Using the combination of these two strategies, a total of 10 participants were recruited.

The participant sample was well balanced with 5 men and 5 women, with representation from Asian, Caucasian, European, and South-Asian ethnic backgrounds. The participants lived in various locations across BC, including Vancouver, Burnaby, Victoria, Maple Ridge, and Kamloops. Of all the participants, 2 were married, 5 were currently in a relationship, and 3 identified themselves as without a partner. One participant self-identified as queer. The age of initial cancer diagnosis for the participants ranged from 1 years old to 16 years old. The cancer diagnoses of this participant sample included Non-Hodgkin Lymphoma, Hodgkin Lymphoma, Acute Myeloid Leukemia [AML], Acute Lymphoblastic Leukemia [ALL], Leukemia (non-specified) and Rhabdomyosarcoma. Treatments received included chemotherapy, radiation, surgery, bone marrow transplant, prostatectomy, and drug therapy such as methotrexate, doxorubicin, and vincristine. Appendix C offers a full demographic profile of the study participants.

### *3.2.3 Data Collection and Analysis*

Data was collected through various sources, including interview recordings, a demographic survey (Appendix D), and by taking field notes immediately following each interview. The interviews lasted 15 to 35 minutes, and were based on a previously constructed



interview guide (Appendix E). Probing questions, such as “please provide me with an example” or “tell me a little more about that experience” were used to help garner more in-depth answers to the interview questions. The demographic survey was completed with each participant immediately following the interview questions. Upon completing the interview process and thanking the participants for their time and contribution, field notes were written down so that my emotions and general feelings evoked by the conversation could be documented. This reflection process led to the slight alteration of the interview guide so that a question regarding gender and fertility, which seemed to be a difficult question for the young ACCS to answer, was refined to increase clarity and ensure that the question was eliciting the desired information.

Data analysis occurred in multiple steps. The first step in conducting data analysis was to create an overall analysis plan, keeping in mind that the analysis should serve to enhance the overall quality of the data (Guest, MacQueen, Namey, 2012). After contemplating the basic analytic approach that would best suit the study structure and goals, it was decided that an exploratory approach would be taken. Exploratory analysis allows for content-driven, inductive reasoning that embraces openness to theory building (Guest, MacQueen, Namey, 2012). The openness of this approach complimented the flexibility inherent to ID and resulted in a methodology that could allow for creative liberation.

Data analysis occurred both during and after the data collection process. Perhaps the most critical form of analysis occurred by taking the time to reflect on the initial pieces of data. As mentioned by Thorne (2008), ID relies on the ability to consider, not only the most obvious concepts in the data, but the deeper meaning of these concepts:

“Interpretive description requires an analytic form that extends beyond taking things apart and putting them back together again. It requires that we learn to see beyond the obvious, rigorously testing out that which we think we see, and taking some ownership

over the potential meaning and impact of the visions that we eventually present as our findings”

Keeping this notion in mind, I read through each interview multiple times to develop a sense of the whole beyond my immediate impressions. This step was also highly important due to the fact that a 3<sup>rd</sup> party transcriptionist was employed to transcribe the interviews. By thoroughly reading over the transcribed interviews multiple times, not only did I gain the opportunity to reconnect with the data, but I was able to cross-check the audio files with the transcribed interviews to fill in any gaps and ensure that no errors were made during the transcription process.

The next component of my analysis was to engage in open-coding, a method that involves breaking-up the data by taking it apart and examining the distinct parts for similarities and differences (Thorne, 2008). To do so, the transcripts were uploaded to NVivo, then coded inductively by selecting sentences or phrases. The evolution of the themes in this study was a product of constant comparative analysis [CCA]. Simply put, CCA ensures that all components of the data are systematically compared to all other data in the data set (Fram, 2013), assuring that the data is comprehensively analyzed rather than having parts of the data disregarded on thematic grounds. CCA is ideal in studies that seek to uncover commonalities and patterns across cases within human experience (Thorne, 2008).

While implementing CCA, the comparison during thematic analysis did not occur in a neat, linear manner, but through a ‘back-and-forth’ process, which allowed for dynamic analysis. A guiding framework, developed by Scott (2004) was used in my analysis to assist in a more thoughtful approach to my constant comparison technique:

- What is [the theme]?
- When does [the theme] occur?
- Where does [the theme] occur?

- Why does [the theme] occur?
- How does [the theme] occur?
- With what consequences does [the theme] occur or is [the theme] understood?

By asking myself the above questions, I could code the interviews into commonalities and notable differences in a thoughtful and strategic manner. A draft coding scheme, inclusive of four themes and sub-themes, emerged after my initial analysis. This initial coding scheme was then shared with Dr. Howard, who offered valuable insight. Dr. Howard challenged me to support my identified themes with ample evidence, and her advice helped ensure that my analysis encompassed the most important concepts in the data.

Throughout the interrogation process during which I coded the interviews toward thematic representation, I utilized another credible tool; the six-phase model of thematic analysis developed by Mann (2016). The 6 phases of this thematic analysis model include: familiarization with the data, coding, searching for themes, reviewing themes, defining and naming themes and writing up. I found that by utilizing Mann's guideline, and having a clear idea as to what I was aiming to accomplish throughout the data analysis process, I could identify themes in the data in a more succinct manner.

Once I had considered the advice that Dr. Howard shared with me regarding my initial coding scheme, my themes were altered slightly to better reflect the experiences voiced by the participants. Further reflection was made as to whether my coding scheme could speak to the primary and secondary research questions. After scrutinizing the emerging themes, diagramming my ideas out on paper, and reflecting on the field notes that were written down following each interview, a final coding scheme was created and discussed with Dr. Howard. These initial results from the data analysis were then shared with Dr. Thorne and Dr. Goddard for their input.

After contemplating the advice received by all members of the supervisory committee, the final themes and sub-themes were consolidated. To further strengthen the data analysis, concepts found in the data which posed as significant outliers were noted and expressed to present a comprehensive depiction of the findings.

#### *3.2.4 Credibility Indicators*

As mentioned by Thorne (2008), building credibility indicators to ensure the research maintains integrity is highly important in ensuring that the final product genuinely reflects the data, and is not biased by the researcher's claims. One strategy to ensure credibility was maintained was to ensure researcher reflexivity. Reflexivity refers to the continuous process of self-reflection applied by researchers to create awareness about their own actions, feelings and perceptions throughout the research process (Anderson 2008, Hughes, 2014). Literature discussing quality in qualitative research has increasingly recognized the importance of reflexivity (Finlay, 1998, Gough 2003, Gilgun, 2006, Smith, 2006, Jootun et al, 2009, McCabe & Holmes, 2009, Lambert et al, 2010, Mann, 2016). Furthermore, reflexivity in research has been documented to improve transparency in the researcher's subjective role, through conducting research and through the analysis phase (Gilgun, 2006).

Researcher reflexivity was enhanced in this study through personal reflection, true to the notion expressed by Polit & Beck (2012) that a study can be improved through the reflection of one's preferences, biases, fears and theoretical inclinations. One method of personal reflection was to use field notes to allow for transparency as to my thoughts and feelings regarding each interview after it was completed. A second method was to make notes throughout the analysis process in the form of analytic memos, to ensure that the methods used for analysis could be tracked and monitored. Not only does this reflexive writing contribute to the transparency of data

analysis, but it increases the dependability of the study by ensuring that the methods used could be recreated in future research (Cope, 2014).

Trustworthiness, or rigor, which refers to the degree of confidence in data, interpretation, and methods used to ensure the quality of a study (Pilot & Beck, 2014) was an important component of this research study. Trustworthiness was amplified through the team approach in which this study was conducted. Collaborating with the members of the research team strengthened the study as it allowed for a reduction in researcher bias through the involvement of multiple view-points (Johnson, 1997). By sharing the transcribed data with my primary supervisor, Dr. Howard, data authenticity regarding the way in which the data was interpreted could be maintained. Sharing the themes and sub-themes found after the initial data analysis process with Dr. Thorne and Dr. Goddard further reduced researcher bias, as the unique perspectives of others challenged the way in which I interpreted and presented the data. The thoughts and opinions of my supervisory committee further encouraged my deeper reflection as to the themes found in the data, and helped the narrative of each themes become more descriptive.

Lastly, it is believed that trustworthiness was positively influenced by the small participant sample from which data was gathered. By focusing on a sample size of 10 individuals, I could spend adequate time and effort exploring each participant's unique understanding of their own fertility, and gain a deeper understanding of the social contexts influencing their experiences. The ability to focus a large amount of time on each participant, during both the interview and the reflection and data analysis phases, resulted in an enhanced credibility and interpretive validity of the study findings (Lincoln & Guba, 2000). I felt that

throughout the process of participant recruitment, interviewing, and follow-up contact, I connected with each participant and gained a strong sense of their experiences and emotions.

### *3.2.5 Ethical Considerations*

Before this study commenced, ethics approval was obtained from the University of British Columbia Research Ethics Board. The approved study poster provided potential participants with basic study information, and did not disclose the monetary compensation that would be given to the participants (Appendix F). The consent form for this study was written carefully to ensure the participants were fully informed about who was conducting the study, the background and purpose of the study, an outline of what study participation would involve, possible harms and discomforts, and possible benefits of the study (Appendix G). As the study sought to explore experiences regarding possible fertility issues, the prospect that the interview questions may elicit negative feelings and emotions was shared with the participants. The consent form clearly outlined that participation was voluntary, highlighting the fact that the participant had the right to withdraw from the study at any point in time or skip any question during the interview without consequence. Participants were given multiple days to read through and sign the consent form and informed written consent was obtained from the participants before any data was collected.

Confidentiality was respected by assigning a unique study code number to each participant in this study. This number did not include any personal information that could identify the participant and was used on any research-related information collected about the participant during the study so that identity could be kept confidential. All documents were kept in a password-protected computer file on the encrypted network of the UBC School of Nursing. Only the research team had access to the data collected in this study. No personal information

will be published in this work or in future work that could be used to identify the participants that were involved in the study.

### **3.3 Chapter Summary**

Throughout this chapter, I have provided rationale for the use of interpretive description and how it has strengthened my ability to gather robust findings that can be readily applied in the real world. This approach was highly useful in gathering an in-depth understanding of what possible infertility means to the young ACCS interviewed, and a sense of what it is like living with an unknown fertility status. I provided a description of how trustworthiness and rigor was maintained throughout the study, most notably through reflexivity and researcher collaboration. Lastly, a description of the study's ethical implications was shared, with attention drawn towards obtaining ethics approval and the ways in which participant confidentiality was maintained.

## **Chapter 4: Findings**

### **4.1 Introduction**

After analyzing the data from all 10 interviews conducted with the young ACCS in this study, wherein I examined the experiences and possible challenges that the participants experienced in relation to having an unknown fertility status, the following 6 themes emerged; (1) living in the unknown is emotionally challenging, (2) possible infertility has an influence on romantic relationships, (3) determining when to seek fertility testing is difficult, (4) discussing fertility is awkward, (5) there is limited fertility-related education, and (6) sex and gender influence the experience of possible infertility. Throughout this chapter, incorporating key quotes from the participant interviews.

### **4.2 Living in the unknown is emotionally challenging**

In this section, I will describe the first theme that emerged in the data: living with an unknown fertility status is emotionally challenging. This theme was the most ubiquitous, in that the negative emotions of fear, sadness and anxiety related to their unknown fertility status were common and complicated the lives of the participants.

#### *4.2.1 Fear*

Both women and men participants described, in great-detail, the fear they felt regarding their future ability to conceive. The participants feared not being able to have their own biological children, having pregnancy complications, having a child whose health would be negatively affected, and disappointing their partner. Similar to other participants, a 26-year-old male survivor of childhood leukemia stated: “It’s been kind of scary because, I mean, I really want to have kids at some point. So it’s kind of a scary thought knowing that maybe I couldn’t.” Likewise, a 23-year-old female Non-Hodgkin Lymphoma survivor described how, “honestly,



what I'm fearful of is like when I get to that point where I want to start having kids I'm just going to be like let down." Statements such as these, shared by the majority of the young ACCS in this study, portrayed the fear they felt for the future, and potentially discovering that they were infertile.

Concerns about pregnancy complications, where "things might go wrong," and the health of a future child were also expressed by multiple participants, who were nervous that because they themselves had had cancer, cancer treatments, and subsequent health effects, their biological children were potentially at risk. This fear was touched upon by a 26-year-old male leukemia survivor, as he recounted: "I've always thought of like, you know, if I could have kids that they could have possible birth defects or could have – maybe they could end up having cancer or something. Like I always worry that oh if I could have kids maybe there's something that could be wrong with them and that's kind of a worrying thing." This young man feared for the health of his future children, and he further quantified his fears as "always" occurring. Therefore, the negative emotions that he described were not simply fleeting feelings that rarely occurred; but were consistent, having significant impact on his emotional wellbeing. This constant fear was described by a few others in this study, while there were also some participants who described their experience of fear as being a fleeting emotion that only affected them on occasion. Not only was there a general sense of fear related to possible infertility, but some participants also described being fearful of letting their partners down if found to be infertile, a challenge I will elaborate on when describing the ways in which an unknown fertility status impacts romantic relationships (section 4.5).

#### *4.2.2 Anxiety*

Anxiety was another common emotion with which the young ACCS in this study struggled to cope. For some, this anxiety interfered with daily life. For example, a 30-year-old male survivor of acute lymphoblastic leukemia described how thinking and reading about potential infertility impacted his ability to fall asleep at night:

“I guess psychologically just when you think about it, you know, that comes up like me just researching it – it’s almost like being in bed and not being able to sleep. And then for some reason you just think about it.”

While some participants experienced less anxiety, or were able to manage their anxiety through strategies such as talking with their family members, others found their anxiety increasingly troublesome over time. A 23-year-old female Non-Hodgkin Lymphoma survivor attributed the rollercoaster of emotions and severe anxiety she experienced to her ignoring the possibility of infertility:

“It’s been really hard not knowing. I think when I first found out it was just horrible... and I haven’t, I didn’t really deal with it and kind of just like swept it under the rug and then I started getting anxiety... Honestly the worst part of cancer I think for me was the recovery and all that comes with recovery... this anxiety and fear, all that stuff that comes after is almost worse. That’s another big thing it’s like such a process – such a grieving process.”

Not only did this participant express how avoiding her feelings caused her anxiety to magnify, but she describes the survivorship phase of cancer as being worse than the experience of the cancer itself. Although this was unique to this participant, others reported struggling with anxiety as a cancer survivor, specifically related to their possible infertility.

#### *4.2.3 Sadness*

Along with feelings of fear, many young ACCS conveyed a sense of sadness associated with their unknown fertility status, most often in anticipation of the possibility that they might

never have children of their own. This anticipatory sadness was exemplified by a 26-year-old male survivor of childhood leukemia:

“It’s sad in a way if I couldn’t [conceive]. Also, I don’t know yet like it’s something down the road like when I’m ready to have children that like I’d want to find out then. Because I know if I find out now I’d be like I guess kind of upset about it so I guess that, that’s part of, that’s the scariest and like saddest part of it, I guess.”

The study participants commonly described how their anticipated sadness led to their decision to wait until they are ready to have children to seek fertility testing.

For some of the participants, sadness, followed by contradictory emotions of optimism, was described as being a confusing combination of emotions, as they reported feeling sad despite not having any concrete evidence that they were infertile. For example, a 23-year-old non-Hodgkin Lymphoma survivor described experiencing anticipatory sadness while also acknowledging the possibility that she might still be able to conceive: “It’s hard because I mean you’re crying and upset but then you don’t even really know you are infertile. So you’re in limbo kind of...I hate being like upset and being like I can never give you kids. But then I’m like well it could still happen I don’t know.” The uncertainty related to fertility and possible outcomes resulted in many of the participants feeling as if they were caught between conflicting emotions of sadness and optimism.

#### *4.2.4 Hope*

Two study participants were hesitant to find out their fertility status because living in the unknown enabled them to maintain hope for the future. For these individuals, living in the unknown, or in “limbo,” served as a sort of protective mechanism against the more challenging negative emotions that would result from confirmed infertility. A 23-year-old female Non-Hodgkin Lymphoma survivor described: “It’s like I want to know but I don’t want to know. I kind of like being in this like ‘oh it might still happen’ rather than like doing it again and

knowing for sure it won't happen, but it is frustrating not knowing." This apprehension toward the finality of receiving fertility test results was again portrayed in the following excerpt taken from an interview with a 22-year old male ALL survivor:

"Researcher: The experience of living in the unknown, how would you describe that?

Participant: It sucks.

Research: You'd rather have an answer?

Participant: Well, yeah, I don't know. Part of me is like, no, I don't want an answer, you know. And part of me is like, yeah, I do want to find out.. but I don't know."

The above quotes draw attention to the way in which these participants vacillated between wanting and not wanting to know their fertility status. The hesitation to obtain conclusive testing and the benefit that living in the unknown served as a means of avoiding possible negative emotions was unique to these two study participants. The remaining 8 participants would have preferred to know their fertility status.

Regardless of whether or not the young ACCS expressed that they were interested in seeking their fertility status at the point in time of the interview, emotions of fear, sadness, and anxiety were particularly challenging.

#### **4.3 Possible infertility influences romantic relationships**

Almost all the participants reported that living with an unknown fertility status negatively impacted their romantic relationships in some capacity. They described this negative impact on the emotional connections in their relationship, the challenge of taking someone else's needs into account, the fear of disappointing their partner, the difficulty of discussing fertility with their loved one, and the potential for their unknown fertility status to lead them to shy away from romantic relationships. Although most participants in this study described the negative influences of possible infertility on their romantic relationships, outliers in the study shared that discussing their unknown fertility status with their partner was in fact able to strengthen their relationship.

The young ACCS in this study commonly identified their unknown fertility status as interfering with the emotional connections within their relationship. A 30-year-old male survivor of ALL elaborated the following influence that his unknown fertility status had on his relationship:

“I mean it, it’s definitely worrisome. It’s, it can linger, you know, somebody who wants to have a family and have kids – it can be a serious hindrance on, I guess, emotional aspects of your relationship with your partner. I mean it’s not something that I would express right away or even have that conversation especially when it’s so unknown.”

The above participant hinted at the fact that because of the hindrance his possible infertility imposed on his relationship, he was hesitant to disclose his unknown fertility status early in his relationship. To further depict these challenges, a 23-year-old female Non-Hodgkins Lymphoma survivor described how being in a committed relationship was the hardest part of facing fertility issues, as she felt compelled to also consider someone else’s needs:

“Well now that I’m in a relationship I think that’s the hardest part. Because it’s not only just about what I wanted for my life, it’s like what he wants too and stuff... and then for fertility it influences your partner and your potential future children that, you know, that you could have – so it’s bigger – it’s just like – it’s a different thing to cope with.”

The fear of letting one’s partner down, and a hesitation regarding the disclosure of one’s unknown fertility status was apparent in multiple interviews. This same participant further elaborated on the stress it caused her to tell her partner about her possible infertility, and how, even though he was supportive, she feared he would be disappointed:

“Ever since I’ve been with my boyfriend the last few years like being with him was a big stress because I had to tell him... He was like: “oh yeah, you had cancer so I expected that to be a side effect”, but I think that he is disappointed. He would never say that to me because he doesn’t want to hurt me, but I think he is disappointed.”

Other young ACCS shied away from certain partners and potential relationships because of their possible infertility and the difficulty of broaching fertility-related discussions. A 36-year-old

male Rhabdomyosarcoma survivor described how his romantic relationships have been shaped by the possibility that he might be infertile:

“I wasn’t sure if I wanted kids or not and I had some partners that definitely they did, and I think that was because I didn’t have the answers about whether or not I could have my own kids or if not – what the next steps would be towards having In Vitro fertilization or a surrogate or any of those other options. Because I didn’t have those answers I didn’t really know how to approach those discussions, and there were some difficult discussions there. I also gravitated towards partners that maybe didn’t want kids.”

For this participant, a lack of fertility-related information and clarity regarding possible options contributed to his inability to approach discussions with his partners in the most effective, positive way possible, which ultimately shaped with whom he sought a relationship.

For another participant, a female AML survivor, the fear of possible infertility prevented her from engaging in any romantic relationship whatsoever. At the age of 30, she described herself as never having been in a long-term romantic relationship, attributing her hesitation in doing so to her possible infertility. Since her teenage years, she had anticipated challenges in discussing her fertility with a future partner, not knowing “how to approach it,” which led her to question whether she should ever have a boyfriend.

Although for most study participants, discussing possible fertility issues with their partner was described as challenging, one participant described talking about his possible infertility with his romantic partners as having a positive influence on his relationship. This 36-year-old male Rhabdomyosarcoma survivor mentioned that opening-up to a partner about fertility, facilitated intimate conversations:

“Because there’s a thing that’s different about me it, it gave me something pretty serious and intimate to talk with partners about early on in a relationship. So often, before I’d ever have sex with any partner, I’d have this conversation with them that I had cancer when I was a kid and there’s, you know, a few things different about me because of that. So for that – on a few occasions, I think, was, was a nice opener to having serious discussions.”

Regardless as to whether the young ACCS recounted positive or negative experiences, it is evident from the interviews that living with an unknown fertility status has a substantial impact on romantic relationships.

#### **4.4 Determining when to seek fertility testing is difficult**

A third theme that emerged from the interviews with young ACCS was the complexity of determining the timing of when to seek information, discuss their fertility testing options, and ultimately undergo fertility testing. This was complicated for participants because readiness to have children, as well as complications associated with fertility testing both factored into their decisions. In this section, I will elaborate on the ways in which these factors challenged the study participants in determining the most appropriate timing for fertility testing.

Readiness to have children was a factor for many participants in this study in deciding when to seek information, as evident in an interview conducted with a 26-year-old male Leukemia survivor. Despite expressing the many challenges, he had experienced while living with an unknown fertility status, when asked when he might want to seek fertility-related information he described: “I don’t know yet... like it’s something down the road like when I’m ready to have children that like I’d want to find out then.” Many other participants provided comparably vague responses, that incorporated the idea that waiting until an older age may be preferable when seeking information about their fertility, yet they lacked a clear idea as to when this “later time” might be.

On a few occasions, the complications the young ACCS associated with fertility testing created heightened uncertainty as to when they believed they should seek fertility testing. One of the complications that the female participants associated with determining optimal time for fertility testing was their current birth control practices. A 23-year-old Non-Hodgkin

Lymphoma survivor described the barriers that prevented her from seeking information related to her fertility status:

“One of the hard parts is the things that I would have to do to go through these tests again I don’t know if I really want to. Like I’d have to go off the pill, I’d have to like for months and then I’d have to do all these like tests again and stuff. And they’re invasive. And like do I wait until I’m really ready to have kids and find out or do I do them all now? While I’m younger like I’m just not sure what the best thing to do is.”

As described by the participant above, the utilization of birth control added a layer of complexity to her decision-making process. In the above quote, she also touches on the “invasive” procedures that she perceived she would have to undergo. In this sense, the complex nature of fertility testing for women, which, to her knowledge, involved hormone-testing and transvaginal ultrasounds, was an important consideration. For men, complications regarding the timing of fertility testing were not based on perceived negative health consequences or the necessity to change their birth control practices, and most of the male and female participants in this study perceived fertility testing as being easier for men.

Throughout the interviews with the young ACCS, it became clear that there were many factors that contributed to the timing of when information regarding one’s fertility status might be sought out. Readiness to have children and complications associated with fertility testing added to the difficulty in determining when the right time may be to seek information regarding their fertility status. Therefore, determining the exact timing as to when to seek information about fertility was a big challenge for the participants in this study, and participants often lacked a clear timeline.

#### **4.5 Discussing Fertility is Awkward**

Fertility was often described by the young ACCS as an awkward topic of discussion, with health care providers, friends and family. In this section, I will highlight the discomfort described



by the young ACCS related to the discussion and communication of various aspects of their fertility and the implications this had for their information and support needs. More specifically, I will interpret how the young ACCS interpreted and communicated their information and support needs in relation to their reproductive health.

According to the young ACCS, the topic of fertility did not come up naturally in conversations with health care providers and the participants were often hesitant to raise the topic themselves owing to the awkwardness of fertility-related discussions. As a result, the participants struggled to find ways to causally weave discussions about their uncertain fertility into conversations, as evident in this passage from, a 30-year-old male ALL survivor:

“I’m not, it’s not really like it’s not something that I just – it’s just, it’s tough because it’s not like an everyday conversation that it would just come up, you know. Like if it would come up it would come up very like, you know, like I think I’ve mentioned, you know, there’s a chance that I might not be able to have kids. Like I’ve kind of really mentioned it like in passing or it’s not really been – it hasn’t really just come up, you know what I mean? Like it’s just . . .”

The vagueness and hesitation in this participant’s response is an indicator of the difficulty young ACCS experience in conceptualizing and discussing their fertility. But this might also indicate the taboo that still exists related to fertility. Throughout many of the interviews, I noticed that when I asked the young ACCS who they discussed their fertility with, their replies were often hesitant and their recounts of fertility-related discussions were minimal.

Just like conversations with health care providers were reported to be challenging to initiate, young ACCS in this study found that conversations with friends regarding possible fertility issues did not arise naturally, and if discussed were not perceived to be supportive. When asked whether she had discussed her concerns and fears regarding possible infertility with her friends, a 23-year-old Non-Hodgkin Lymphoma survivor replied: “I don’t really talk to friends. I do a little bit and like they just feel sorry and stuff. But it’s not like a regular thing I

talk about.” This quote also illuminates that participants did not initiate fertility related conversations because they wanted to avoid the pity of their friends. Other participants recounted unsupportive interactions with friends that prevented survivors from engaging in future conversations. For example, a 30-year-old female AML survivor recalled that: “I didn’t discuss this with my friends. The thing is I think a few of them know but when I was a teenager because I got really upset about it- they might have found out that way... but then I don’t think we ever, ever talked about it afterwards so I really didn’t know if they actually remember.” Though this unsupportive communication happened long ago, it took on great significance for the participant, limiting with whom she confided in going forward. Similar to the experiences of other participants, the above quote also supports the notion that young ACCS do not rely on their friends for support regarding their fertility. Due to the lack of communication that young ACCS in this study reported having with their friends regarding their fertility, it seems that they did not seem to rely on their peers for related support.

Not only were conversations regarding fertility difficult for young ACCS to have with their health care providers and friends, but these conversations were also described as being difficult to initiate with their parents. Young ACCS described feeling awkward when having to discuss fertility with their parents, and reported that they felt that their parents also found it to be an awkward topic to discuss. The difficulties perceived by the participants in this study regarding fertility-related discussions with their parents was often due to the lack of sufficient fertility-related knowledge that they perceived their parents to have. This unpreparedness to answer questions was evident in the recounting of a 36-year-old male Rhabdomyosarcoma survivor:

“I had some discussions with my parents but I always felt like they didn’t really know how to talk about it, and they also probably didn’t have a lot of information when it came to these questions about fertility and what the implications would be for me as an adult. I think they were just a little bit – they weren’t against talking about it, but they didn’t have

the answers so they were a little bit shy and awkward about it. I think they would have been better if they – from somewhere – got some support earlier on too.”

The participants further explained that fertility-related conversations with their parents were challenging and awkward because of the inextricable link to intimacy and sex, as exemplified by another quote from the above participant:

“I think that the fertility probably isn’t the big awkward part – it’s probably more the sexuality about it which makes it awkward for especially parents and kids in my situation. Along with the conversation of whether or not I could have kids comes the conversation of my sex life, and I think that if I was putting myself in my parent’s shoes or someone else I wouldn’t know where to draw that line. That might lead me to shy away from the whole conversation altogether.”

Not only did this young man mention that his parents lacked the education and knowledge to discuss fertility, but he described the taboo of discussing sex with his parents. This finding was common for many young adults in this study, as it seemed that discussing fertility was awkward for both parents and survivors’ due to its connection with sex and intimacy.

#### **4.6 Limited Fertility-Related Education across the Cancer Trajectory**

Nine of the 10 participants in this study reported, to some extent, that they felt as if they had received limited education regarding their fertility status. This included both during the initial cancer diagnosis, cancer treatment phase, as well as throughout the follow-up period of survivorship. This lack of fertility education was attributed to their young age at cancer onset, a lack of elaboration on the finer details of fertility issues, and insufficient knowledge possessed by certain health care providers.

##### *4.6.1 Younger age at cancer onset*

Participants in this study described their young age at the time of cancer diagnosis, treatment, and at the time of their oncology follow-up consultation as contributing to their lack of education about their risk for infertility. Those who were younger encountered difficulty

understanding the provided information, did not receive timely education, and were frustrated that fertility-related discussions were not directed to them, but rather to their parents. For example, the following participant, a 22-year-old male AML survivor who was diagnosed and treated at the age of 12 years, described how much of the fertility-related information he had received was not actually directed at him:

“I think I was like twelve and my doctor, my oncologist, mentioned to my parents, oh yeah, fertility, oh yeah, probably can’t have kids or whatnot. I actually didn’t know. I was kind of like, wait, I can’t have, you know, I can’t do that, what? And then he kind of explained it to me. And I kind of wish it was different, you know, because it wasn’t really directed at me. It was like oh, he’s too young to kind of understand or whatnot.”

When this same participant was asked what he knew about his fertility status, and what he thought his risks could be, he responded: “I don’t know much to be honest. They [Health care providers] don’t really talk about it like, honestly, they don’t really talk about it that much.”

Limited fertility-related education was also a challenge among those treated in their teenage years as well as those seeking information as a young adult, as evident in this quote from a 31-year-old male AML survivor:

“You know, when I’m like nineteen and twenty and asking like, oh what’s the like deal with my fertility? And sometimes I’d kind of get like, oh well, are you married? And I’d say no, they’d say, oh, don’t worry about it. They’re like, you know, that’s something to worry about later.”

Through the description of encounters such as this, shared by many of the participants in this study, it became clear that health care providers had rarely discussed fertility, and that health care providers were prone to making the assumption that fertility should not be discussed with the participants in this study throughout the trajectory of their cancer experience. As children with cancer, fertility conversations were often directed at their parents, while as adolescents or young adults in the late stages of treatment and survivorship phase, these conversations continued to be sparse due to the assumption made by health care providers that they were still

too young. By failing to see fertility as being a priority for their young patients, or putting the conversation about fertility off until a later date, health care providers marginalized the educational needs of this patient population, and often left the young ACCS feeling as if their thoughts, feelings and information needs related to potential infertility were insignificant.

#### *4.6.2 Insufficient Fertility-Specific Information*

There is considerable evidence in these interviews to suggest that the described lack of fertility-related education is closely related to the inability of practitioners to elaborate on the finer details of fertility resources, fertility testing, and the current research regarding the prognosis and expected outcomes for childhood cancer survivors. This section will provide the various ways in which the participants of this study described this notion. A 23-year-old female Hodgkin Lymphoma survivor described an experience where, although fertility was mentioned briefly as a bullet point on a pamphlet, further education on the topic was not offered. When asked what kind of education she received regarding her fertility, she replied:

“Next to nothing. I mean when I was thirteen, I don’t remember much. I do remember going through all of the chemo drugs I was going to receive and getting a pamphlet for each one of them. And it was like short term effects, long term effects, rare, serious effects kind of thing. And I remember fertility being on there and not knowing what it was or what it meant. Generally, sexuality is not even touched on in any cancer care.”

When asked to elaborate on this experience, she further highlighted her lack of clarity about the details of the physical impact her cancer treatments had on her reproductive organs:

“So I mean the only conversation I can actually remember is in my long-term follow-up and that’s because like you’re given this thirty page questionnaire. And a lot of them are like are you concerned about fertility? So I always mark the box yes I have that concern. And it’s always so brief. It’s like, okay, so you’ve had this drug, it’s a small dose so you’re probably fine – how regular are your periods? I’m like, okay, yeah, they’re mostly regular – it’s fine, but then it’s sort of dismissed. There’s no like feelings about it – there’s no like what does it mean that I’m infertile? Is that to do with my ovulation? Is that to do with like the actual structure of my uterus like fallopian tubes or ovaries? There’s a lot of things that can go wrong, what exactly has this drug done to my body

which could potentially make me infertile. I mean I understand why you may not be able to get into that but at the same time I think it's important to know."

The experience shared by the young woman above portrays a sense of feeling "dismissed" by health care providers when seeking fertility related information. This impression of avoidance and dismissal of the expressed concerns or questions posed by the young ACCS resulted in participants feeling like their health care providers failed to provide them with enough information. A 26-year-old male Leukemia survivor also touched on the lack of detailed education he received, and how even though it was mentioned to him as a general statement, the specifics regarding his fertility were never discussed in detail:

"Well I've always like basically probably starting around like puberty, I guess, when my parents told me was that there's was always the possibility that like I might not be able to have kids. So I think at that time I didn't think much of it because I was a young teenager. So but that, that's basically kind of when I started wondering about it. And then pretty much from there that's all I was ever told. I wasn't told about like, you know, any other options or like why that was. I mean I knew it was because of my treatment but like I wasn't really told anything beyond that other than, oh, you might not be able to have kids. And then it wasn't until probably only the last couple of years at my annual check-ups that they started saying, oh, you know, like you could be infertile. So it was like – it was kind of a gap between when I was told initially of like a young teenager until like I was actually told like as an adult about it. It didn't really seem like a priority for them to tell me that. So I didn't really remember being told kind of as a young teenager so I was finally officially told I guess I was kind of like, oh, well I didn't really know about that... There really wasn't much of like a counseling side or like, you know, a compassionate side of that – it was kind of like cut and dried. Oh, you know, you could just get tested kind of thing."

The above quote suggests that not only were the finer details regarding the physiology and biology of possible infertility left out, but the emotions tied to infertility were often ignored. For many participants, this was noted to be of importance, as fertility was thought of as a priority for the young ACCS, and because the emotions associated with fertility were described as being significant.

#### *4.6.3 Health care providers lack fertility knowledge*

Health care professionals were described by most participants as being ill-versed on the topic of infertility after cancer, resulting in a lack of proactive fertility-related discussions, as well as leaving the participants with numerous unanswered questions regarding their individual fertility prognosis. A 22-year-old male AML survivor described that because his oncologists did not seem well educated about his infertility risk, their conversation felt awkward:

“Yeah, there needs to be more information for sure. Like my doctors were, you know, they didn’t bring it up. And it was still – like even with the oncologist it seemed like kind of an awkward topic a little bit, you know. And they didn’t really know much about it. They kind of... it wasn’t really their field.”

Another participant acknowledged that he felt uneducated about his fertility risks due to the lack of fertility discussions he has had with his family doctor. Although he acknowledged this initial lack of education, this 36-year-old male Rhabdomyosarcoma patient mentioned the positive effect that the existence of Vancouver’s Late Effect, Assessment and Follow-up [LEAF] clinic has had on his experience:

“There haven’t been many. I think it was up until recently - up until the LEAF clinic came along I had pretty limited information. And I didn’t really know if there were answers out there or where to go. So I had a family doctor – and still do - and they had limited information about what the implications might be. I think when I was a teenager I had some questions but I didn’t really know where to go to ask them...Now that I’ve got some specialized attention through the LEAF clinic I have a lot more answers. I think it’s pretty simple that they can just refer me to fertility specialists now.”

Many individuals in this study expressed that their educational and informational needs regarding their fertility were not met, however, it seems that the addition of the LEAF clinic in Vancouver has been able to assist with the follow-up care needs, including fertility education, of this patient population.

#### **4.7 Fertility testing, and confirmed infertility perceived to be more detrimental to women**

The final theme that emerged from the interviews provides insight into the ways in which the study participants perceived sex and gender to influence the experience of living with an unknown fertility status. Although both men and women described fertility to be of personal importance, and possible infertility as negatively influencing their lives, the majority postulated that fertility testing and confirmed infertility would be detrimental to women but not men. This was attributed to both biological and gender differences.

##### *4.7.1 Sex-specific differences*

Study participants perceived the female body to be more complicated and complex. They suggested that the anatomy and physiology of the female reproductive system made it harder for females to undergo fertility testing and related treatments as they are much more invasive than for males. For example, fertility testing for women was assumed by participants as including multiple tests such as blood-tests and ultrasounds, while male fertility testing was viewed as a much easier process that simply required a sperm sample. Therefore, fertility testing was seen to be a greater nuisance to women, as it was viewed as an interruption to the young female ACCS birth control practices, as well as hormone therapy treatment. When describing the differences between males and females, a 23-year-old Non-Hodgkin Lymphoma woman survivor stated:

“That’s a big difference too is that I have to think about birth control, not only because I’m in a relationship, but also because I need the hormones because women’s bodies are more – a lot more complicated right? Like if I don’t have those hormones then I start going into menopause and then my bones will not be the same and I’ll get hot flashes. But a guy who is infertile probably doesn’t have to deal with that stuff like they have a test and they find out. For me it’s not easy it’s like I have to sacrifice a lot of stuff just to have these tests done.”

A 30-year-old male ALL survivor also touched on the differences between male and female reproductive roles, and how missing the opportunity to go through pregnancy might have more



of a psychological impact on a woman, whereas he believes he might find it easier to adopt a child. Of the 5 men interviewed, 3 discussed their willingness to adopt, while out of the 5 women in the study, only 1 woman identified that she was open to adoption. When asked how he thinks men and women might be impacted differently, this participant's response was:

“I would shy away about taking a guess on how it would affect a female, but I would imagine it would be harder, just because of the, you know, with women having babies it's more, I guess, emotionally different for them to have children so it might affect them psychologically more. But I guess in terms of like one thing I've always thought is that if I can't have children then even though it's obviously different, I mean I would adopt. I guess that might be a little bit harder to do because the females actually carry the baby, and it might be different psychologically that way.”

As iterated above, there was an assumption by numerous participants that because females physically carry the child from fertilization to birth, they are psychologically affected to a greater degree than the parent who does not carry the child.

#### *4.7.2 Gender roles and identities*

The participant's ideas regarding expected gender roles and gender identity also influenced the ways in which they perceived men and women to experience possible infertility. One such notion, expressed by multiple participants, was that when women miss out on child-bearing, they also miss out on the opportunity to engage in an important social experience wherein they bond with other child-bearing women. However, this shared experience of child-bearing was not considered relevant to men, as exemplified by a 30-year-old female AML survivor:

“I guess for me, for the women's part, because I'm thirty and my friends are mostly around my age, you're getting to the point where people are talking about having babies and whatnot. And then sometimes you get friends that don't know about your situation say something about me being a woman and having a baby. And you're like, that's kind of in my face, but they didn't know... Because for a woman, they are the child bearer – I think it's probably harder on a woman than a man.”

Men in the study also perceived that the expectation of a mother to carry her own baby could be challenging for a woman unable to do so because they might feel inferior to those who are able to conceive. A 36-year-old Rhabdomyosarcoma survivor described how he would feel if gender roles were reversed:

“I think just right off the bat that if I was a woman and there were questions about my fertility I think I would be a lot more anxious. And I think that’s because in our society there’s still much more duty placed on the woman to be able to provide a child. So like as a man if I, if I have a partner and we want to have kids a really viable option is to just get a sperm donor. And my partner still gets to go through pregnancy and have a child. But that’s a lot – that’s not the same at all if the gender role is reversed. So I think there would be more of a feeling of inferiority for a woman.”

This same participant continued to discuss the implications on each gender when missing out of the childbearing experience, and how the differences in social interactions between groups of men and the social interactions between groups of women might contribute to differences. The following quote further exemplifies the perceived importance of the shared social experience of bearing children between women:

“I think that groups of men and women on their own like me with my male friends and women with their female friends there’s more – there’s more of an emphasis with groups of female friends on fertility. I’m thinking of one of the partners I had in the past that really did want kids and she had more urgency around it. She really wanted to have kids when her friends were having kids, she didn’t want to miss out on that shared experience. And, and I’m sure that there’s similar things with men that its really nice to have kids when your friends are having kids but it’s not quite the priority and the focus in what I’ve seen with my social circle... Just being a woman fertility is more of a priority”

In addition to the presumed shared social experiences associated with pregnancy, the study participants also perceived that women share a more intimate bond with a child than do men, and thus, the potential emotional toll of not bearing one’s own child was greater for women. Echoing other participants’ descriptions of the ways in which gender might influence the experience of possible infertility after cancer, a 22-year-old AML survivor stated: “I think it might be harder on

females just because, I don't know, I think there's more intimacy with the child and whatnot. I think it's hard on both sexes but I think it probably would be a little bit harder on a woman".

Drawing from the description of men and women's gender roles provided by the participants, it seems that for women, fertility and childbearing are seen as a primary responsibility, and thus ought to be their priority. On the other hand, bearing children was not described as being a fundamental social expectation for men.

#### **4.8 Chapter Summary**

In this chapter, the findings from analysis of the interviews were presented. The 6 themes that emerged from the qualitative data analysis provide a unique perspective into the experiences of the 10 young ACCS that were involved in the study, and identify some of their fertility-related challenges that these young adults face. The first theme, which addressed the emotional aspect of living with an unknown fertility status, portrayed an array of negative emotions including fear, sadness, anxiety and grief that were common in young ACCS. The second theme found in the data was that living with an unknown fertility status seemed to influence romantic relationships, as most participants described a negative influence on their current relationship or the impact it had on choosing a partner. Thirdly, determining when to seek fertility testing was described as being difficult, as timing as to when to seek fertility related information was influenced by various factors including readiness to have children and the perceived complications involved with fertility testing. The fourth theme that I described in this section was that determining how to bring up the topic of fertility was explained by participants as being an awkward and unnatural, not only in conversations with their health care providers, but also when talking with their parents and friends. The fifth theme I discussed was the overall lack of fertility-related education that the young ACCS had recalled been received by their health care providers.

Finally, the last theme identified in this chapter was that women were perceived by most of the participants as being more negatively influenced by possible infertility than men, due to differences noted between male and female anatomy, expected gender roles, gender norms and social differences. It is anticipated that by capturing the most prevalent themes in the data, and supporting these themes with relevant quotes from the interviews conducted, new perspectives will be gained as to how follow-up care for this unique population can be improved upon.

## **Chapter 5: Discussion & Recommendations**

The final chapter of this thesis will provide a discussion of the strengths and limitations of my study, as well as possible practice implications of the findings, inclusive of thoughtful recommendations for health care providers regarding their practice behavior and the provision of fertility-related education. A fertility resource, constructed specifically for patients in BC will be shared in hopes that it can be built upon by health care professionals to better suit the needs of the local patient population of young ACCS. Lastly, recommendations for future research will be made.

### **5.1 Strengths & Limitations**

#### *5.1.2 Strengths*

It is worth discussing the numerous strengths of this study. First, the diversity within the research team offered a strong foundation for collaboration. Two established scholars from the field of nursing, one practicing oncologist, and myself – a Master's of Science in Nursing and Masters of Public Health dual degree student, brought together a strong variety of expertise. Dr. Thorne, one of the previously mentioned scholars in the field of nursing, is a professor at the University of British Columbia and Associate Dean for the Faculty of Applied Science. Dr. Thorne is also the founding theorist of ID, the methodology applied in this study and a world-renowned expert in qualitative research methods, chronic illness and communication. Therefore, her knowledge regarding the application of ID ensured that the study could robustly emulate this methodology's primary goals and positive traits.

Another strength in this research study was the diversity seen within the participant sample. Sex was well balanced, as out of the 10 participants there was an even number of males and females. There was also a mixture of ethnic backgrounds, and a variety of cancers and

cancer treatments for which the young ACCS had been exposed. Additionally, the individuals lived in a variety of geographic locations, thus adding insight from participants in both urban and more rural areas. It is also worth noting that one of the participants self-identified as queer. Her unique perspective as to how coping with possible infertility was influenced by her sexuality, and how having the same-sex partner influenced her experience, was truly helpful.

### *5.1.3 Limitations*

Although this study has numerous strengths, there are also several limitations. One limitation of this study is the small sample of participants involved. It is discussed by Morse (2015) that as researchers, we know that the size of the sample depends on the nature of the phenomenon, whether it is concrete versus subjective in nature, the amount of complexity and scope of the phenomenon, as well as how much has been discovered about the topic in previous research. Morse (2015) further explains that trying to predetermine the sample size for a study is a futile task, as if the sample is too small, it can result in data that does not reach saturation, and superficial conclusions. Keeping this in mind, a potential weakness of this study may be the fact that it included ten participants. Had this sample been larger than ten participants, the study findings may have had a greater ability to reach saturation on a larger spectrum of topics, and transferability of the results to other young ACCS in various models of care nationally and internationally may have been better achieved. Although it is believed that the findings can show the experiences of the ACCS's involved in the study, it is important to note that had a different group of individuals been interviewed, different conclusions may have been made.

Another possible a limitation to this study may be due to the lack of clarity in the participant's memories, as the interviews were conducted many years after the participants underwent their cancer treatments and obtained education regarding their follow-up care. Thus,

the participant's recollection of the education and information they had received regarding fertility may not be completely accurate. Acknowledging the possibility of this unintentional recall bias is especially important when reflecting on the details the young ACCS provided regarding the fertility-related education they had received as children.

## **5.2 Key Findings & Implications for Practice**

This thesis work provides some beginning understanding of the complexity of challenges that young ACCS face, as well as sex and gender differences that require further research. Although it is a small, qualitative study, the alignment of the findings with what has been found in previous studies lends hope that it will support insights that can enhance sensitivity to patient needs. As Thorne (2014) so eloquently states:

“While we can generally assume that formal clinical procedural change will require systematic review of evidence, there is much within the practice world that is highly sensitive to the findings of well-timed, articulate, and powerful qualitative research presentation, especially if it matches the “clinical instincts” that our audiences are already predisposed to favor.”

In this manner, I hope that this small study, extending upon what has already been written about this population, may contribute to the applicability of this study's findings in the real-world.

The study findings provide insight into the challenges survivors face related to uncertain fertility that could inform current practice. Although this study was conducted from a nursing lens, many different health care providers can draw from the study findings apart from nurses, including nurse practitioners, general practitioners, oncologists, psychologists, and social workers. The results from this study suggest that increasing healthcare providers' awareness regarding the critical role of support for managing possible fertility challenges after cancer would be greatly beneficial for young ACCS. Many of the study participants stated that they felt

that their health care provider lacked appropriate knowledge and skills regarding possible fertility issues, resulting in insufficient support. This aligned with the findings shared by Gorman et al (2013) who pointed out that patient informational needs regarding fertility and parenthood issues after cancer were not being adequately addressed, as medical professionals lacked clarity on how to approach these particular needs. Therefore, health care providers could greatly improve the provision of more precise, comprehensive patient-care if they could expand their knowledge regarding certain fertility issues after cancer. This recommendation is supported by findings in a study by Robbins et al (2015) who found that a key contributor in the lack of fertility-related care may be due to a lack of health provider's confidence in discussing fertility. More specifically, health care providers could further improve their practice by becoming more aware of the emotional underpinnings tied to the experience of living with an unknown fertility status, as it became clear through the interviews that living with an unknown fertility status is emotionally challenging. The emotional challenges prevalent in my study were supported by Yi et al (2015) who described the young ACCS in their study as experiencing emotional distress, as well as concerns about their romantic and peer relationships.

The perplexing experience of wavering between anxiousness and hope for future children often meant that young adult ACCS experienced a complexity of emotions in relation to considering their own fertility. This finding is in line with a study done by Gorman et al (2011), who reported that although young cancer survivors expressed hope about having a family, many also felt anxious and worried that they would be unable to have their own children. Due to the range of emotions experienced by cancer survivors, health care providers may need to alter their approach of care and become more involved in discussions regarding their patient's emotional response to possible infertility. This could be done by health care providers during their



interactions with young ACCS, by asking survivors about the emotional challenges they are experiencing, and inquiring about how they might be able to support these patients. It is recommended by Hohmann et al (2011) that sustainable patient counselling should become part of clinical guidelines and communication training for medical staff working with oncological patients. Perhaps health care providers who are involved with this patient population might also find the resource created from this study to be a helpful tool in their practice, in that it provides a number of local community resources, such as support groups and counselling, which they can share with their patients.

Another recommendation for practice is for health care providers to become more aware of the possible influence that sex and gender can have on the experience of living with an unknown fertility status. Because findings from this study suggest that men and women have distinct challenges when facing possible fertility issues, with women being described as more negatively influenced, it is also highly important for health care providers to keep in mind the impact that the care they provide for their female patients may need further attention. This finding was supported by by Armuand et al (2015), where women were described as being more vulnerable when facing risk for infertility', as women reported more negative experiences related to patient-provider communication regarding fertility-related aspects of cancer treatment, as well as negative emotional reactions to the risk of infertility and challenges related to handling uncertainty regarding future fertility. As a perceived gender-role in my study portrayed that both men and women viewed women as missing out on an important shared social experience, perhaps practitioners could enhance the care they provide their patients by connecting their patients with others facing uncertain fertility, so that a platform for an alternative shared experience can be provided.

As identified in Chapter 4, fertility discussions were described as complex, often due to the awkwardness felt by patients, parents and practitioners associated with the topic. Therefore, a further recommendation for clinicians is that they might enhance fertility-related communication by altering their approach to discussions, perhaps by allowing for more open conversations with their patients regarding fertility-related matters during regular check-ups. In this study, determining when and how to discuss their fertility was complicated for the young ACCS, often due to a feeling of “awkwardness” regarding fertility discussions. Similarly, Goosens et al (2015), found that participants’ considered fertility to be an intimate issue comparable to sexuality, which was often discussed only in a safe and confidential atmosphere. In this study, cancer was also a sensitive topic for young participants because it was associated with terrible suffering and death, and the combination of these sensitive issues led to avoidance.

A few young ACCS in this study mentioned feeling dismissed when asking their health care providers about their fertility status when younger. This finding was mirrored by Gorman et al (2011), wherein several participants discussed disappointment that their doctors were hesitant to talk with them about fertility issues and postponed the discussion until they were older and at a time in life when they were deemed ready to have children. In light of this, practitioners could potentially help to alleviate difficulties by initiating “awkward” conversations by readily offering information about fertility related issues to cancer survivors, and by making their patients aware that they are available to discuss fertility at whatever age the patient feels ready. This suggests that some survivors begin considering their fertility at a younger age and continue to do so over many years. As such, fertility discussions would be appropriate with some adolescent survivors and age alone is insufficient to determine the appropriate timing. This finding was also supported by Crawshaw et al (2010), who suggested that using chronological age or pending marriage, for

example, as a prompt for or focus of intervention may be less helpful than seeking to understand its personal and social significance for those affected. Thus, assumptions that use a ‘stage’ approach to development and see fertility as of little concern to survivors until permanent adult relationships or parenthood are contemplated should be replaced by practitioners engaging in patient-specific support by being open to discussing fertility with their patients at any age.

Lastly, it recommended that those involved in providing care to young ACCS become more aware of the impact that possible infertility can have on romantic relationships. As survivors in this study drew attention to a variety of relationship concerns that have the possibility to negatively interfere with their ability to move toward emotional and physical intimacy in relationships, it may be imperative that barriers in relationships are addressed. Most of the survivors in this study found that discussing their fertility and disclosing their potential infertility to their partners was challenging. Likewise, Thompson et al (2013) described that while half of the interviewed survivors in their study reported a willingness to discuss the factual aspects of their cancer history with romantic partners, the other half of the participants described being more reluctant, if not fearful, of disclosing such an important piece of personal information. Thus, as emerging adulthood involves exploration of more mature and intimate relationships, health care practitioners may improve the care they provide for this specific patient population by discussing the challenges experienced in romantic relationships, and by assisting patients in accessing alternate resources such as relationship counselling.

#### *5.2.1 Policy change*

Implications of this research could help guide health care leaders in the consideration of practice or policy change to aid practitioners in providing fertility education in more depth and at more appropriate times. Several participants in this study identified fertility as just being another

box on the long list of cancer long term or late effects presented to them on a follow-up questionnaire. To present fertility-related follow-up care in a different way, it is recommended from this research that fertility issues encompass a distinct topic of discussion brought up by health care providers at the time of cancer treatment and during follow-up care, so that the importance of this topic is not overlooked. If brought up in this way, health care providers may be better able to set aside the time in the health visit to have these important discussions. It seems from this research that a new policy, which can clarify the importance of initiating conversations regarding fertility from the time of diagnosis, as well as what fertility-related topics should be discussed, may pose as a helpful tool in moving forward towards better, more comprehensive practice.

#### *5.2.2 New Information Pamphlet*

To assist with the recommended practice changes, and to enable a more fluid translation of knowledge from this study into practice, a draft of a new information resource was formed, which includes suggestions as to what information could be helpful for young ACCS to receive during the survivorship phase. Based on the recommendations given by the participants in this study, this resource has been designed so that it can be further enhanced by health care providers practicing at the LEAF clinic in Vancouver, and perhaps provided as a resource to their patients once complete (Appendix H). This pamphlet is inclusive of the information needs identified during the interviews, including background information regarding how cancer treatments can influence fertility, fertility testing resources, fertility treatments to assist with conceiving, alternate options to conceiving, and success stories. This resource is specific to British Columbia, and encompasses information regarding the resources available within the province.

### **5.3 Recommendations for Future Research**

The results from this study indicate a need for further research to better understand the many influences that can impact the experience of possible fertility issues for young ACCS. One such influence found in the data was that of sex and gender, as findings indicate that the experience of living with an unknown fertility status impacted men and women differently. In terms of sex, it would be interesting to further explore how male and female biology impacts the young ACCS experience in seeking testing and information regarding their fertility status. For example, is complexity associated with the female body and fertility testing common in the reflection of other survivors, and could a lack of knowledge regarding this complexity play a role in male and female perceptions? Gender posed as another interesting influence that requires further investigation, as the impact of gender-roles and social constructs emerged. Perhaps it might be worth exploring how the development of educational material, such as information regarding health services, could be tailored to men and women in different ways.

Another topic warranting further investigation is the influence of possible infertility on romantic relationships. Findings from this study suggest that living with an unknown fertility status has an overwhelmingly negative impact on the relationships between young ACCS and their partners. However, the outlier experience indicated that having an unknown fertility status had the ability to strengthen a relationship. Further research to validate this finding, from the perspective of patients and their romantic partners, is needed to examine how possible infertility can influence romantic relationships. A longitudinal study, which could show how possible infertility impacts romantic relationships over time may be highly beneficial.

Lastly, although there was only one participant who self-identified as queer in this study, it would be of much interest to conduct a study with a more diverse sample including individuals

who identify with various genders and sexualities. In this study, the participant who identified as queer mentioned her experience as being very different due her sexuality, and she herself highlights the need for future research involving others like herself. One study, conducted by Russell et al (2016), found that while the LGBTQ and heterosexual participants in their study reported similar challenges approaching romantic relationships post-diagnosis, heterosexual survivors were more likely to report fertility concerns as affecting romantic relationships. An additional finding from this study was that LGBTQ survivors seemed more open to raising non-biological children, and not becoming a parent, than heterosexual survivors. In this sense, it was elaborated upon by the researchers that LGBTQ cancer survivors may display more adaptive coping with respect to relationships and fertility loss. As in the study by Russell et al, the one participant who self-identified as queer in this study described herself as being more open to alternate forms of conception than many of the non-LGBTQ participants. However, due to the small representation of LGBTQ patients in this study, further research is needed to explore the differences that one's sexuality and gender-identity can have on the experience of living with an unknown fertility status.

## **5.4 Chapter Summary**

In conclusion, this qualitative study provides some beginning insights into the experiences of young ACCS as they navigate an unknown fertility status. The study findings support the need to modify current healthcare practices and address gaps in the health care system, including the lack of discussion, education, and involvement of cancer survivors in forming their fertility care plan.

For the participants in this study, fertility-related discussions with health care providers were often brief, with limited opportunities for patient involvement and obtaining relevant and

personal information. If survivors are asked earlier on in the follow-up care period to identify their personal struggles regarding fertility management, and the degree of involvement they would like their health care provider to have in discussing and overcoming these issues, it might increase the likelihood that their needs are incorporated and addressed in ongoing care. This would provide the patients with the opportunity to share their thoughts, fears, expectations, and desires regarding their fertility, resulting in more personal care.

A resource to provide condensed, relevant information regarding fertility education and resources, such as the brochure created using the recommendations provided by the study participants, could be helpful in alleviating misconceptions and answering questions. The results of this study also suggest further research is warranted to examine the many factors that influence the experience of managing an unknown fertility status. By continuing to explore the experience of living with an unknown fertility status through the eyes of the young ACCS, it is hoped that a better understanding of the health care needs specific to this patient-population can be obtained.

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## Appendix A: Literature Review Matrix

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
<p>(1) <b>‘Will I be able to have a baby?’ Results from online focus group discussions with childhood cancer survivors in Sweden</b></p> <p>J. Nilsson<sup>1</sup>, A. Jervaeus<sup>1</sup>, C. Lampic<sup>1,2</sup>, L.E. Eriksson<sup>1,3,4</sup>, C. Widmark<sup>5,6</sup>, G.M. Armuand<sup>1</sup>, J. Malmros<sup>7,8</sup>, M. Marshall Heyman<sup>7,8</sup>, and L. Wettergren (2014)</p>	To determine what adolescent and young adult survivors of childhood cancer think about the risk of being infertile.	Qualitative study, with a cross-sectional design, data collected through 39 online focus group discussions during 2013	<p>Cancer survivors previously treated for selected diagnoses were identified from The Swedish Childhood Cancer Register (16–24 years old at inclusion, ≥5 years after diagnosis)</p> <p>N = 133</p>	The analysis resulted in the main category “Is it possible to have a baby?” including five generic categories: Risk of infertility affects well-being, dealing with possible infertility, Disclosure of possible infertility is a challenge, Issues related to heredity and Parenthood may be affected. The risk of infertility was described as having a negative impact on well-being and intimate relationships. Furthermore, the participants described hesitation about becoming a parent due to perceived or anticipated physical/psychological consequences of having cancer.	Recommended that health care professionals systematically address fertility issues and future parenthood; such communication should include adequate valid information and support.
<p>(2) <b>A multidimensional scale to measure the reproductive concerns of young adult female cancer survivors</b></p> <p>Jessica R. Gorman &amp; H. Irene Su &amp; John P. Pierce &amp; Samantha C. Roberts &amp; Sally A. Dominick &amp; Vanessa L. Malcarne (2013)</p>	Concerns about fertility and parenthood are important to many young adult (YA) female cancer survivors. This study aimed to develop a new scale to comprehensively measure these concerns.	Scale development involved: (1) seven focus groups, (2) administering surveys to young adult female survivors and conducting principal components analysis and (3) the identification of preliminary construct validity evidence.	<p>Focus groups (N=22), Survey (N=204)</p> <p>Participants (age, 18– 34 years). Age at diagnosis ranged from 6 months to 30 years.</p>	Our results suggest that the RCAC scale is a reliable and valid measure of reproductive concerns among YA female cancer survivors.	The multidimensional RCAC scale identifies a range of concerns that are not included in the one previously existing scale and has been described as having significant potential for future research use.

<b>Study, Author, Year</b>	<b>Purpose</b>	<b>Methods</b>	<b>Sample</b>	<b>Findings</b>	<b>Recommendations for further research or practice</b>
<b>(3) Impact of Childhood Cancer on Emerging Adult Survivors' Romantic Relationships: A Qualitative Account</b>  Amanda L. Thompson, Kristin A. Long, and Anna L. Marsland (2012)	To document emerging adult survivors' perceptions of their romantic relationships through a descriptive qualitative study.	Individual phone interviews focused on past and present romantic partnerships.	Eighteen female survivors of childhood cancer, ages 18–25	Themes from coded transcripts included redefined life priorities and perspective, concerns with disclosure of cancer history and emotions, negative body image as a result of illness and treatment side effects, and worries about fertility and health of future children. Survivors related these concerns to their histories of childhood cancer and discussed the impact on the development and maintenance of romantic relationships.	These findings suggest a number of testable hypotheses for future research, have the potential to inform the construction of new measures that more accurately evaluate social functioning of childhood cancer survivors, and emphasize the importance of ongoing assessment by health care providers of developmentally salient issues like love/romance.
<b>(4) How do you feel about fertility and parenthood? The voices of young female cancer survivors</b>  Jessica R. Gorman & Samantha Bailey & John P. Pierce & H. Irene Su (2011)	This qualitative research study explores the fertility and parenthood concerns of reproductive-age female cancer survivors and how they make parenthood decisions.	Participants attended one of seven focus groups. Used cross-case, inductive analysis to identify themes.	Population- and clinic-based recruitment methods were used to identify a diverse group of survivors between the ages of 18 and 34 years. Our final sample size = 22 participants.	The following main themes were identified: (1) A hopeful but worried approach to fertility and parenthood, (2) Frustration with a lack of choice or control over fertility, (3) Young survivors want information about their fertility, (4) Young survivors want better continuity of care in survivorship, (5) Cancer diagnosis and related fertility problems introduce relationship challenges, and (6) Decisions about parenthood are complicated.	This study illustrates that young survivors could benefit from improved information regarding their fertility and parenthood options throughout survivorship, better coordination of medical care, and support navigating many emotional and practical issues that arise when considering their reproductive and parenthood options.
<b>(5) Sex Differences in Fertility-Related Information Received by Young Adult Cancer Survivors</b>	The aim was to investigate male and female cancer survivors' perception of fertility-related	Questionnaire responses were gathered from a study-specific questionnaire	Cancer survivors diagnosed from 2003 to 2007 identified in population-	The majority of male participants reported having received information about treatment impact on fertility (80%) and FP (68%), and more than half of the men banked	Our results show marked sex differences regarding the receipt of fertility-related information and use of FP. There is an urgent need to develop fertility-related information adapted to female

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Gabriela M. Armuand, Kenny A. Rodriguez-Wallberg, Lena Wettergren, Johan Ahlgren, Gunilla Enblad, Martin Höglund, and Claudia Lampic (2012)	information and use of fertility preservation (FP) in connection with cancer treatment during reproductive age.		based registers. Inclusion criteria: age 18 to 45 years at diagnosis and had a specific type of cancer. 484 survivors (60% response rate) completed a postal questionnaire.	frozen sperm (54%). Among women, less than half (48%) reported that they received information about treatment impact on fertility, and 14% reported that they received information about FP. Only seven women (2%) underwent FP.	patients with cancer to improve their opportunities to participate in informed decisions regarding their treatment and future reproductive ability.
<b>(6) Romantic and Sexual Relationships, Body Image, and Fertility in Adolescent and Young Adult Testicular Cancer Survivors: A Review of the Literature</b>  Melissa Y. Carpentier, J. Dennis Fortenberry (2010)	To present a summary of existing knowledge regarding the effect of testicular cancer along four broad domains, including romantic and sexual relationships, body image, and fertility.	A total of 37 studies were reviewed, and were gathered from PubMed, MEDLINE, and PsycINFO databases.	Most research consists of older adult testicular cancer survivors, with very little research attention afforded to adolescent and young adult survivorship.	Concern with post-treatment fertility is an issue for more than half of some samples of testicular cancer survivors [10]. A few survivors purposefully choose to ignore issues related to potential post-treatment fertility, citing inappropriate timing for starting a family as a primary reason. Many participants report regret that fertility may have been unnecessarily sacrificed because of a lack of knowledge regarding available fertility-preservation treatments. Reduced fertility is related to decreased quality of life among testicular cancer survivors .	Sexual function (and thereby fertility) and body image have also often been compromised through treatment and thereby represent additional targets for continued research. In particular, additional qualitative research is needed that explores, in survivors' own words, the effect of testicular cancer on such domains. The gathering of such data will allow for identification of survivor needs and the subsequent development and testing of interventions that address such needs.

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<b>(7) Late reproductive effects of cancer treatment in children, young cancer survivors</b>  Jido & Cruickshank, (2015)	This is a discussion piece on late reproductive effects on childhood cancer survivors	Two experts in the field express their concerns & knowledge on the issue, and offer four different case studies to exemplify the various issues that can occur for this particular population.	N/A	N/A	Better reproductive counselling is needed
<b>(8) Desire for children, difficulties achieving a pregnancy, and infertility distress 3 to 7 years after cancer diagnosis</b>  Gabriela M. Armuand & Lena Wettergren & Kenny A. Rodriguez-Wallberg & Claudia Lampic (2014)	The aim was to investigate desire for children, difficulties achieving a pregnancy, and infertility distress among survivors 3 to 7 years after cancer treatment in reproductive age.	A postal questionnaire including study-specific questions, the Short-Form 36 Health Survey and the Fertility Problem Inventory, was sent to 810 survivors, and 484 participated (60 % response).	Cancer survivors were identified in national population-based cancer registries. Eligible subjects presented with selected cancer diagnoses between 2003 and 2007 between the ages of 18 to 45.	Most survivors who had a pretreatment desire for children still wanted children 3–7 years after treatment, and this group was characterized by young age and being childless at diagnosis. In addition, a substantial group of survivors (n= 55, 17 %) that did not have a pretreatment desire for children had changed their mind about wanting children after treatment. About a third of the survivors with a desire to have children had experienced difficulties achieving a pregnancy after the cancer treatment, and an unfulfilled desire to have children was associated with worse mental health.	Health professionals in cancer care need to be aware that patients' plans for future children may change, particularly if they are young and childless. All patients of reproductive age should be provided with adequate information about the impact of cancer treatment on future fertility and fertility preservation.
<b>(9) Communication Difficulties and the Experience of Loneliness in Patients With Cancer Dealing</b>	To explore communication difficulties and the experience of loneliness among patients with cancer	Qualitative study based on grounded theory principles.  Grounded theory approach using the	21 Female and 7 male patients with cancer with potential fertility problems as a	Loneliness was a central theme in the experience of potential fertility loss among patients with cancer. Feelings of loneliness resulted from communication difficulties	Healthcare professionals must be attentive to signs indicating loneliness regarding fertility concerns, and they should provide adequate information and appropriate guidance to



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<b>With Fertility Issues: A Qualitative Study</b>  Joline Goossens, MSc, RM, Ilse Delbaere, PhD, MSc, RM, Dimitri Beeckman, PhD, MSc, RN, Sofie Verhaeghe, PhD, MSc, RN, and Ann Van Hecke, PhD, MSc, RN (2015)	dealing with fertility issues.	constant comparison method; data collection (semi-structured face-to-face interviews) and analysis occurred simultaneously.	result of treatment.  From one university hospital and two general hospitals in Flanders, Belgium.	between the patient and members of his or her social environment or healthcare professionals because of several underlying processes and influencing factors.	support patients. Professionals need further training to improve knowledge and skills.
<b>(10) Quality of Life, Self-Esteem and Worries in Young Adult Survivors of Childhood Cancer,</b>  N.E. Eveld, Grootenhuis, P. A. Voute, R. J De Haan, C. Van Den Bos (2004)	This study assessed quality of life, self-esteem and worries in young adult survivors of childhood cancer compared to a group of young adults with no history of cancer.	All participants completed the MOS-24 (Medical Outcome Study Scale), a Worry questionnaire consisting of three scales (cancer-specific concerns, general health concerns, present and future concerns), and the Rosenberg Self-Esteem Scale.	Participants were 400 long-term survivors (LTS) of childhood cancer (age range 16–49 years, 45% female) who had completed treatment an average of 16 years previously and 560 persons (age range 16–53 years, 55% female) with no history of cancer.	Small to moderate differences were found in mean MOS-24 scores between the LTS group and controls (range effect sizes 0.36–0.22). No significant difference was found in the mean self-esteem scores between LTS and controls. Female LTS had more cancer-specific concerns than male LTS. In several related areas of general health, self-image and dying, the LTS group reported less worries than controls, but LTS worried significantly more about their fertility, getting/changing jobs and obtaining insurance's.	Further research exploring determinants and indices of quality of life and worries in LTS is warranted.

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<p><b>(11) Surviving childhood and reproductive-age malignancy: effects on fertility and future parenthood</b></p> <p>Jaime M Knopman, Esperenza B Papadopoulos, James A Grifo, M Elizabeth Fino, Nicole Noyes (2010)</p>	<p>This review discusses survival statistics and the medical and psychological effects of cancer on fertility treatment and future parenthood, including health risks for afflicted patients, their gametes, and offspring.</p>	<p>Literature review. References for this review were identified by searches of Medline and PubMed Only papers published in English between January, 1979, and June, 2009, were included.</p>	<p>N/A</p>	<p>Despite the desire of many cancer patients to maintain fertility, several factors hinder the initiation of this discussion. In a survey given to oncologists, knowledge of resources, practice behaviours, perceptions of patient characteristics, and quality of discussion were identified as barriers to discussing fertility preservation. Discussions are further limited for paediatric patients, likely because of the consent process, issues surrounding the experimental nature of procedures, and gamete disposition in the event of death.</p>	<p>In summary, despite concerns regarding parenthood and pregnancy after cancer, maintaining fertility is a viable and often crucial option for many patients, and therefore must be addressed. A dedicated multidisciplinary team consisting of medical or surgical oncologists, a reproductive endocrinologist, genetics counsellor, perinatologist, and psychologist are required. This is currently achievable in centres where the disciplines, expertise, and interest exist.</p>
<p><b>(12) Fertility and cancer—a qualitative study of Australian cancer survivors</b></p> <p>Rebecca Penrose &amp; Lisa Beatty &amp; Julie Mattiske &amp; Bogda Koczwara (2011)</p>	<p>This study aims to assess the fertility concerns among cancer survivors aged 50 and under as part of a larger study investigating the survivors' concerns regarding fertility, sexuality and parenting.</p>	<p>Cancer survivors who were at least 1-month post- treatment were invited to a recorded interview. The patients were identified from an oncology database and invited to participate via letter or during clinic consultation. The participants were recruited until saturation of themes was achieved. Transcripts were coded thematically, with greater emphasis</p>	<p>Twenty-five survivors (19 women) were inter- viewed. The median age was 37 (range 24–50). Median time since completion of treatment was 7 months. Twenty were married or in a relationship; 18 had children at the time of diagnosis. Two became pregnant after</p>	<p>Four themes were identified: (1) Fertility represents more than child-bearing capacity: potential fertility loss was a concern for participants, irrespective of their desire for future children; (2) Assumed infertility: There was a tendency for participants to assume that they were infertile; (3) Lack of information regarding decision-making and fertility: The respondents reported a perceived lack of consideration of fertility at diagnosis by medical professionals, and this impacted upon the decision-making process; and (4) Participant</p>	<p>Fertility is an important concern for young cancer survivors. There is a need for strategies regarding information provision and support for cancer patients with regard to these concerns.</p> <p>The present findings have significant clinical implications on information provision and support regarding fertility to cancer patients. This study highlights the importance of changing the way of how health care providers engage patients in fertility discussions. The discussion regarding fertility and cancer needs to not only deliver information that is appropriate in</p>

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		given to frequently raised themes.	treatment.	recommendations: The respondents wanted more information and for support services to be offered.	content, format and timing to the needs of the patient but also to engage the patient in order to facilitate decision-making and the desired degree of involvement in the process.
<p><b>(13) A pilot study about female adolescent/young childhood cancer survivors' knowledge about reproductive health and their views about consultation with a fertility specialist</b></p> <p>J. Kim, J. E. Mersereau (2015)</p>	Impaired fertility and reproductive health after cancer treatment is an important quality-of-life issue among female childhood cancer survivors (ACCSs). This study aims to measure female ACCSs' knowledge about their reproductive health and their exposure to and views about reproductive counseling (RC).	This is a cross-sectional, web-survey study.	Female CCSs aged 18 to 45 years who were diagnosed with cancer before age 21 years and currently had no evidence of disease.	Knowledge about reproductive health after cancer treatment was severely limited within this sample of highly educated survivors (91% educated beyond high school), who provided correct answers only 32% of the time. Only 9 and 5% of the women had pursued RC with a fertility specialist before and after cancer treatment, respectively. The majority thought they had not been provided enough information about reproductive health. White ethnicity (p, 0.001), higher annual income (p 1/4 0.007), and higher education level (p 1/4 0.02) were significantly associated with a positive opinion about RC.	A limited number of CCSs took advantage of RC in spite of their high interest in and limited knowledge about reproductive issues. Targeted referrals for RC may allow for improved decision making about reproductive options.
<p><b>(14) Fertility preservation in young cancer patients—too little, too late?</b></p> <p>Helen Louise Robbins &amp; Arooba</p>	To characterize local practice of fertility care for younger women that had survived cancer.	A retrospective audit of electronic and paper records was conducted in a large NHS District General Hospital	N/A	Only a subset of potentially eligible patients were referred to fertility services. Furthermore, in breast cancer patients, there were often considerable delays between diagnosis and first documented discussion, with an average delay of 34 days. Fertility is an	An increased awareness of fertility-related matters and a drive for early discussion and referral are needed to tackle this complicated subject in younger women with cancer.

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Zahoor & Kevin Jones (2015)				important issue that is often inadequately addressed, with missed opportunities and unacceptable delays.	
<b>(15) Fertility Issues for Young Adult Survivors of Childhood Cancer</b>  Zebrack, Casillas, Nohr, Adams, Zeltzer (2004)	As a qualitative exploratory study, this work identifies concerns, attitudes, and behaviors that may be associated with childhood cancer survivors' reproductive capacity.	As part of a semi-structured interview assessing the impact of cancer on long-term survivors' quality of life, survivors were asked if they had physical limitations as a result of their cancer or treatment, and if having cancer has affected their ability to have children.	A convenience sample of 32 childhood cancer survivors between the ages of 19–37 and at least five years beyond diagnosis	These data are organized around two major themes: (1) survivors' reproductive capacity and (2) their attitudes, experiences and concerns about children and parenting. Fifty-nine percent of survivors reported that they are uncertain about their fertility status, and half recall a parent or health care provider ever mentioning potential reproductive problems associated with their past cancer treatment.	As childhood cancer survivors transition into adulthood, they appear to lack critical information necessary to make informed choices about family planning. Comprehensive and quality follow-up for long-term cancer survivors should include education in previous diagnosis, treatment, and potential late effects, with an emphasis on wellness, health maintenance, and health promotion. To achieve these goals, fertility assessment, including evaluation of survivors' knowledge about their own reproductive capacity and counseling, should become part of that comprehensive follow-up.

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<p><b>(16) Women more vulnerable than men when facing risk for treatment-induced infertility: A qualitative study of young adults newly diagnosed with cancer</b></p> <p>Gabriela M. Armuand, Lena Wettergren, Kenny A. Rodriguez-Wallberg &amp; Claudia Lampic (2014)</p>	<p>This qualitative study investigates newly diagnosed cancer patients' experiences of fertility-related communication and how they reason about the risk of future infertility.</p>	<p>Informants were recruited at three cancer wards at a university hospital. Individual semi-structured interviews were conducted, focusing on three domains: experiences of fertility-related communication, decision-making concerning fertility preservation, and thoughts and feelings about the risk of possible infertility. Data was analyzed through qualitative content analysis.</p>	<p>Eleven women and 10 men newly diagnosed with cancer participated.</p>	<p>The analysis resulted in three sub-themes, 'Getting to know', 'Reacting to the risk' and 'Handling uncertainty', and one main theme 'Women more vulnerable when facing risk for infertility', indicating that women reported more negative experiences related to patient-provider communication regarding fertility-related aspects of cancer treatment, as well as negative emotional reactions to the risk of infertility and challenges related to handling uncertainty regarding future fertility.</p>	<p>HCP must keep the following in mind: The fact that available FP methods for women are more demanding and time-consuming than those currently available for men, could be an explanation to the lack of satisfying fertility-related communication between health professionals and female patients. Lack of shared decision-making among women concerning future fertility may cause feelings of losing control and it is therefore necessary to improve the fertility-related communication targeted to female cancer patients. This could include the development and use of decision aids for women diagnosed in child-bearing age, providing adequate time for consultation of fertility aspects and involving partners in these discussions.</p>
<p><b>(17) Effects of gender roles, child wish motives, subjective well-being, and marital adjustment on infertility-related stress: a preliminary study with a Hungarian sample of involuntary</b></p>	<p>The aim of the study is to investigate the infertility-related stress in a Hungarian infertile population and examine the effects of gender roles, child wish motives, subjective well-being, and marital</p>	<p>Validated self-report questionnaires measuring the factors of the conceptual framework were taken in the study carried out in a sample of 53 people attending the fertility unit of a Hungarian clinic.</p>	<p>Participants recruited at the Fertility Unit of Department of Obstetrics and Gynecology of University of Debrecen. Men and women attending the unit were eligible for the</p>	<p>Infertility-related global stress, infertility-related social concerns, and general health problems have more intensive effect on women than on men. Women from the infertile group scored higher their femininity and lower their general health than the reference population. Infertile men believe deeper in meaning of life than women or reference population.</p>	<p>In frame of further researches, qualitative methods could be used to discover the proper conception about gender roles and the value of a child in the society. Future studies with social and personal factors should be conducted in international setting. A follow-up study is also recommended to see the change in effect of each factor.</p>

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<b>childless men and women.</b>  Reka Eszter Cserepes, Janos Kollar, Tama's Sapy, Tewes Wischmann, Antal Buga (2012)	relationship on the experience of infertility according to our self-constructed conceptual framework.		study if they met the following criteria: (1) had been trying to conceive for a year or more, (2) had sufficient Hungarian knowledge to complete the questionnaires.	Femininity traditional gender role concepts, general health, marital relationship strongest role to predict stress caused by infertility.	
<b>(18) Having Children after Cancer A Pilot Survey of Survivors' Attitudes and Experiences</b>  Leslie R. Schover, Lisa A. Rybicki, Beth Anne Martin, Karen A. Bringelsen (2002)	To gain information regarding cancer survivors' attitudes, emotions, and choices with regard to having children.	A questionnaire was received by 283 patients from the Cleveland Clinic Foundation tumor registry who were diagnosed before age 35 years, were age 18 years or older at the time of the survey, and were free of disease. The SF-36, a measure of health-related quality of life, was included, as well as questions about demographic and medical background, reproductive and fertility history, and a variety of concerns about having children after cancer.	43 men and 89 women who had had cancer at various sites. Their mean age at diagnosis was 26 years and the mean time since diagnosis was 5 years.	19% percent have significant anxiety that their cancer treatment could impact negatively on their children's future health. Of women, 18% fear that a pregnancy could trigger a cancer recurrence. Only 57% received information from their health care providers about infertility after cancer. Other reproductive concerns were discussed less often. Only 24% of childless men banked sperm before treatment. About 80% of the sample viewed themselves positively as actual or potential parents. Feeling healthy enough to be a good parent after cancer was the strongest predictor ( $P = 0.001$ ) of emotional well-being as measured by the Mental Component Score of the SF-36.	Future studies should explore further the difficult choices that cancer survivors must make about having children. Factors that should be examined include the influence of age at cancer diagnosis on attitudes about fertility and having children, and the extent to which conservative treatments that preserve fertility affect patient satisfaction and overall quality of life. Cancer patients should be compared with matched samples of healthy couples or couples with other causes of infertility to understand better the unique ways in which the cancer experience influences fertility and attitudes about parenting.

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(19) <b>Men, women, gender and cancer</b>  C. Moynihan (2002)	Argumentative paper based on the knowledge, experience and expertise of the writer.	N/A	N/A	N/A	This paper argues for a gender relational approach in the context of cancer care bearing in mind that conceptual problems are intertwined with methodological approaches. Hitherto, research in the field of psycho-oncology has used a positivist methodology that separates sex from 'gender'. Men's and women's biological difference dictates their sexual destiny. Moreover, adjustment to cancer is conceptualized as lying <i>within</i> the patient, usually women. A contextual framework of a person's experience is negated.
(20) <b>Cancer Patients' and Partners' Psychological Distress and Quality of Life: Influence of Gender Role</b>  Pikler, Brown (2010)	To examine whether cancer patients and partners differed in psychological distress, and quality of life as a function of their gender-role identities.	Three hundred cancer patients and romantic partners of cancer patients were surveyed regarding their psychological distress, quality of life, and gender-role identity.	Participants were 188 male and female cancer patients, 1 transgender patient, and 111 male and female romantic partners of cancer patients ( $N = 300$ ) who were solicited from two outpatient cancer clinics and one cancer support center in a Midwest urban city.	Individuals who ascribed to either a masculine or an undifferentiated gender-role identity, regardless of whether they were a patient or a partner, were more at risk for developing depressive symptoms as compared to those who ascribed to a feminine or androgynous gender-role identity. Also, partners of cancer patients were more at risk for developing anxiety symptoms as compared to cancer patients, regardless of gender-role identity. There were no significant differences among gender-role identities or role status in regard to quality of life.	Findings of the current study provide evidence that gender-role socialization may be more salient than sex to the development of depressive symptoms among cancer patients and their romantic partners. These findings suggest that practitioners need to, as a regular practice in medical and psychological health-care settings, assess for psychological distress among cancer patients and their partners. For reasons described earlier, psychological distress may be present and/or undetected among partners, those with poorer physical functioning, younger individuals, and those who ascribe to masculine and undifferentiated gender roles.

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<p>(21) <b>Gender relations and health research: a review of current practices</b></p> <p>Joan L Bottorff, John L Oliffe, Carole A Robinson and Joanne Carey (2011)</p>	To explore how conceptualizations of gender relations have been integrated in health research.	A scoping review of the existing literature was conducted. The key terms gender relations, gender interactions, relations gender, partner communication, femininities and masculinities were used to search online databases.	Two reviewers independently screened 811 abstracts, and identified 95 potentially relevant manuscripts.	Through analysis of this literature we identified two main ways gender relations were integrated in health research: a) as emergent findings; and b) as a basis for research design. In the latter, gender relations are included in conceptual frameworks, guide data collection and are used to direct data analysis.	Gender relations are an exciting and emergent area in need of more attention from health researchers. Health-related behaviors do not operate in isolation and need to be understood in the context of interactions within and between men and women across personal, interpersonal and institutional levels. A better understanding of gender relations and health in research and policy will have direct implications for health interventions and guide decisions about whether group, dyadic or single point programs are likely to be effective. In addition, this research has great potential to challenge relational patterns that are so often taken-for-granted and contribute to reducing gender inequalities in health.
<p>(22) <b>Infertility education: Experiences and preferences of childhood cancer survivors.</b></p> <p>Cherven, B. O., Mertens, A., Wasilewski-Masker, K., Williamson, R., &amp; Meacham, L. R. (2016)</p>	The purpose of this study was to assess young adult survivors' previous experience in receiving education about their risk for infertility and determine their preferences for infertility education at various time	Participants were asked to complete an investigator-developed survey that asked questions regarding education they may have received about their risk, or lack of risk, for infertility, at different time points during their cancer experience:	Survey mailed to 342 randomly selected 18 to 25-year-old survivors.	Only 36% of survivors' report receiving education about risk for infertility at diagnosis, 39% at end of therapy, and 72% in long-term follow-up/survivor clinic visits. Survivors consistently identified their oncologist as a preferred educator at each time point. Although almost all participants identified wanting education at diagnosis, this time point alone may not be sufficient.	End of therapy and survivorship may be times this message should be repeated and adapted for the survivor's needs and developmental stage: conversations about the impact of cancer treatment on future fertility should be ongoing.



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	points during and after treatment.	diagnosis, end of treatment, and survivorship/long-term follow-up.			
<p><b>(23) Sex, gender, and health: The need for A new approach.</b></p> <p>Doyal, L. (2001)</p>	This brief analysis has highlighted the complex links between biological sex, social gender, and health.	Expert in the field shares her ideas.	N/A	Men are now following the example of women in drawing attention to the links between gender, health, and health care. The health of both sexes is influenced by biological factors including, but not confined to, their reproductive characteristics. Socially constructed gender characteristics are also important in shaping the capacity of both women and men to realize their potential for health. Gender inequalities in access to health promoting resources have damaging effects on women's wellbeing. Men face particular problems because of the relation between masculine identities and risk taking.	More research, policy change and health promotion is needed regarding the topic of gender and health. Greater sensitivity to sex and gender is needed in medical research, service delivery, and wider social policies.
<p><b>(24) Patient Counselling on the Risk of Infertility and Its Impact on Childhood Cancer Survivors: Results from a National Survey</b></p> <p>Cynthia Hohmann, Anja Borgmann-</p>	The primary objective was to investigate how many CCS being diagnosed from 1980 to 2004 were able to recall adequate patient counselling at the time of diagnosis. The second	In 2006 the questionnaire was piloted. In 2008 the German Childhood Cancer Registry ( <i>Deutsches Kinderkrebsregister</i> [DKKR]), which has been recording patient data nationwide since	752 CCS treated in Berlin	Especially in light of diminished pregnancy frequencies among CCS, counselling at the time of diagnosis and additional ongoing counselling which goes beyond information brochures is strongly recommended (Green et al., 2003). In clinical practice, patient counselling is often not	Sustainable patient counselling should become part of guidelines and communication training for medical staff working with oncological patients. It should become obligatory to inform CCS and/or their parents about possible long-term complications of chemo- and radiotherapy and adequate treatment options with regard to their fertility before

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
Staudt, Rosa Rendtorff, Simone Reinmuth, Steve Holzhausen, Stefan N. Willich, Guenter Henze, Lutz Goldbeck & Thomas Keil (2011)	objective was to examine how recalled patient counselling was related to psychosocial dimensions such as gender, age at time of diagnosis, education, and its impact on offspring-related attitudes and behavior.	1980, sent questionnaires to 4,689 adult CCS with valid address information (Borgmann-Staudt et al., 2009).		done in a way that it can be recalled by former patients and is therefore lacking sustainability. Inadequate counselling can lead to a lack of use of preservation methods. In a sample of 163 CCS of which about one third had diminished fertility at the time of the assessment, only two participants (one male and one female) had sperms/ovarian tissue cryopreserved before therapy (Rendtorff et al., 2010). In fact, one has to consider that there are no widely accepted methods for fertility preservation for prepubertal boys and girls. For female adolescents embryo cryopreservation is rarely used, as female adolescents often do not have a partner for sperm donation (Cohen, 2009). Nevertheless, these limited possibilities should not restrain from patient counselling.	therapy and repeat it after treatment when reaching adolescence and adulthood.
<b>(25) A comparison of heterosexual and LGBTQ cancer survivors' outlooks on relationships, family building, possible infertility, and patient-doctor fertility risk communication</b>	Little research about cancer-related infertility has examined the experiences and needs of lesbian, gay, bisexual, transgender, or queer (LGBTQ) cancer survivors. This re- search	Semi-structured telephone interviews conducted with adolescent or young adult (AYA) cancer survivors were coded for themes. Interviews consisted of questions about pre- and post-diagnosis thoughts	56 CCS	While LGBTQ (n = 22) and heterosexual (n = 34) survivors reported similar challenges when dating post-diagnosis, heterosexual survivors were more likely to report fertility concerns as affecting romantic relationships ( $p < .05$ ). LGBTQ survivors seemed more open to raising non-biological children or not becoming a parent than	Further research and interventions facilitating information exchange about dating, fertility risks, and family building options may be valuable to LGBTQ and heterosexual cancer survivors.

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
Andrea M. Russell & Kathleen M. Galvin & Maya M. Harper & Marla L. Clayman (2015)	seeks to understand how LGBTQ survivors are similar to or different from heterosexual survivors with respect to cancer treatments' effects on relationships, plans for parenthood, and fertility preservation decision making.	about relationships, parenthood, possible infertility, and how information about fertility risks was received.		heterosexual survivors. LGBTQ survivors generally reported being satisfied with or indifferent to the information that they were given regarding fertility loss, despite reporting receiving similar amounts of information as compared to heterosexual patients ( $p < .10$ ).	
<b>(26) Fertility Preservation Preferences and Perspectives Among Adult Male Survivors of Pediatric Cancer and Their Parents</b>  Daniel M. Stein, David E. Victorson, Jeremy T. Choy, Kate E. Waimey, Timothy P. Pearman, Kristin Smith, Justin Dreyfuss, Karen E. Kinahan, Divya Sadhwani, Teresa K. Woodruff, and Robert E. Brannigan (2014)	In this study, we set out to determine the preferences, concerns, and attitudes toward fertility preservation of adult male survivors of pediatric cancer and their parents.	We conducted 3 focus groups. Grounded theory methodology was used for the identification and analysis of recurrent themes expressed by survivors and their parents in the course of focus group discussions.	15 male survivors of pediatric cancer (age at diagnosis: mean=14, range: 10–20; age at study: mean=35, range: 25–47) and 2 groups with a total of 7 parents of survivors.	Themes most frequently expressed by survivors included concern regarding long-term treatment effects and a retrospective desire for fertility impairment to have been discussed when they were originally diagnosed with cancer. Parental themes included the same hindsight desire, as well as reliance upon the treating oncologist for direction in selecting the course of treatment, and an acknowledgment that input from a specialist in fertility preservation would have been beneficial.	Although future reproductive potential was not consistently reported as a source of apprehension when diagnosed with cancer, both survivors and their parents noted it to be a paramount concern later in life. Parents and survivors both reported that fertility preservation discussions should be routinely incorporated in the clinical context of a pediatric cancer diagnosis. Looking forward, our study findings may be practically applied towards the development of educational materials for physicians and medical teams to facilitate fertility preservation discussions between providers, patients, and their families.

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
<p><b>(27) Fertility concerns among child and adolescent cancer survivors and their parents: A qualitative analysis</b></p> <p>Sarah J. Ellis, Claire E. Wakefield, Jordana K. McLoone, Robertson &amp; Richard J. Cohn (2016)</p>	<p>The purpose of this study was therefore to examine the fertility and family planning concerns of young cancer survivors and their parents.</p>	<p>Semi-structured interviews were administered</p>	<p>young cancer survivors (&lt;20 years) and their parents (n D 97). Fertility related concerns were reported by 45 participants (46.4%).</p>	<p>Young people with cancer and their families are concerned about their future fertility. They report unmet needs for information regarding fertility risks and options for preservation. They have concerns about not being able to have biological children as well as how this may impact on future relationships and emotional well-being. It is important to use their perspectives to guide future interventions to address the concerns of the survivor as well as the family.</p>	<p>Several resources provide promising avenues for information and guidance. However, there are few rigorously evaluated interventions that have been informed by patient/family preferences and perspectives, and that are specifically targeted at this unique population. Young cancer survivors and their families may benefit from personalized consultations including fertility counseling and psychological support services as well as systematic long-term follow-up.</p>
<p><b>(28) Fertility as a priority among at-risk adolescent males newly diagnosed with cancer and their parents</b></p> <p>James L. Klosky &amp; Jessica L. Simmons &amp; Kathryn M. Russell &amp; Rebecca H. Foster &amp; Gina M. Sabbatini &amp; Kristin E. Canavera &amp; Jason R. Hodges &amp; Leslie R. Schover &amp; Michael J. McDermott (2015)</p>	<p>Although adult survivors prioritize fertility and parenthood, this issue remains unexplored among adolescent males. This study examined future fertility as a priority (relative to other life goals) at time of diagnosis for at-risk adolescents and their parents.</p>	<p>Participants were asked to prioritize eight life goals: to have school/work success, children, friends, wealth, health, a nice home, faith, and a romantic relationship. Patients' parents (fathers, n = 30; mothers, n = 61) rank-ordered the same priorities for their children.</p>	<p>Newly diagnosed adolescent males (n = 96; age = 13.0–21.9 years) at increased risk for infertility secondary to cancer treatment.</p>	<p>“Having children” was ranked as a “top 3” life goal among 43.8 % of adolescents, 36.7 % of fathers, and 21.3 % of mothers. Fertility ranked third among adolescents, fourth among fathers, and fifth among mothers. Future health was ranked the top priority across groups, distinct from all other goals (<math>p &lt; 0.001</math>), and fertility ranked higher than home ownership and wealth for all groups (<math>ps &lt; 0.001</math>). For adolescents, low/moderate fertility risk perception was associated with higher fertility rankings than no/high risk perceptions (<math>p = 0.01</math>).</p>	<p>Good health is the most important life goal among adolescents newly diagnosed with cancer and their parents. In this relatively small sample, adolescents prioritized fertility as a top goal, parents also rated fertility as being more important than home ownership and financial wealth. Health care providers should communicate fertility risk and preservation options at diagnosis and facilitate timely discussion among families, who may differ in prioritization of future fertility.</p>

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
<p><b>(29) Worries of childhood cancer survivors in young adulthood</b></p> <p>Jaehee Yi, Min Ah Kim, Jina Sang (2015)</p>	<p>Childhood cancer survivors worry about many issues related to their cancer history. As they grow older, additional issues may emerge. This study of a sample of Korean young adults aims to understand childhood cancer survivors' worries.</p>	<p>Qualitative in-depth interviews were conducted over the phone or in person. Participants ranged in age from 20 to 36, were diagnosed before age 19, and had completed treatment at the time of the study.</p>	<p>A purposeful sample of 28 childhood cancer survivors</p>	<p>Through qualitative interviews, survivors' worries were identified in the following five themes: romantic relationships and marriage, fertility and the health of future children, work and social life, family, and physical health. The study's findings support the importance of understanding the worries of childhood cancer survivors in young adulthood and the need for developing services and programs to help survivors acquire the appropriate social skills and coping strategies to mitigate their worries.</p>	<p>This study highlights the need for developing follow-up psychosocial interventions to help childhood cancer survivors acquire the appropriate social skills and coping strategies concerning employment and relationships, to mitigate their worries in these areas. Direct interventions for relieving worries and instilling confidence and a sense of security could be effective for those at risk for detrimental psychological health issues. Such interventions would be beneficial in helping childhood cancer survivors overcome chronic worries and plan for their future.</p>
<p><b>(30) 'Swimming against the tide' – the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer</b></p> <p>M. A. Crawshaw (2010)</p>	<p>Psychosocial research into cancer-related fertility has concentrated on fertility preservation or adult survivors' concerns. This study reports on its hitherto unreported impact over the time from diagnosis to survivorship.</p>	<p>An exploratory qualitative study was conducted to gather self-reported personal experiences over time of managing cancer-related fertility matters. Participants were recruited between 2004 and 2006 by senior doctors at routine appointments at three English regional pediatric oncology units.</p>	<p>Thirty-eight men and women aged &lt;30, diagnosed as teens, were recruited to an exploratory qualitative study.</p>	<p>Four key experiences of managing fertility matters influenced, or were influenced by, the aftermath of cancer treatment: (1) prioritizing 'normality' and marginalizing fertility; (2) fertility concerns compromising 'normality'; (3) ongoing impairments/health concerns mediating fertility matters; (4) fertility concerns dominating the cancer legacy. Professional and social networks provided few opportunities to ask questions, receive information, process feelings or develop strategies. Beliefs about the extent of fertility damage didn't</p>	<p>Opportunities for dialogue should be offered regularly across health and social work disciplines given fertility's psychological and social as well as medical significance.</p>

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
				necessarily relate to information received. For some, fertility matters affected identity, well-being and life planning as well as reproductive function.	
<b>(31) Fertility of Female Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study</b>  Daniel M. Green, Toana Kawashima, Marilyn Stovall, Wendy Leisenring, Charles A. Sklar, Ann C. Mertens, Sarah S. Donaldson, Julianne Byrne, and Leslie L. Robison (2009)	This study was undertaken to determine the effect, if any, of treatment for cancer diagnosed during childhood or adolescence on fertility.	We reviewed the fertility of female participants in the Childhood Cancer Survivor Study (CCSS), which consisted of 5-year survivors, and a cohort of randomly selected siblings who responded to a questionnaire. Medical records of all members of the cohort were abstracted to obtain chemotherapeutic agents administered; the cumulative dose of drug administered for several drugs of interest; and the doses, volumes, and dates of administration of all radiation therapy.	There were 5,149 female CCSS participants, and there were 1,441 female siblings of CCSS participants who were age 15 to 44 years.	The relative risk (RR) for survivors of ever being pregnant was 0.81 (95% CI, 0.73 to 0.90; $P < .001$ ) compared with female siblings. In multivariate models among survivors only, those who received a hypothalamic/pituitary radiation dose $> 30$ Gy (RR, 0.61; 95% CI, 0.44 to 0.83) or an ovarian/uterine radiation dose greater than 5 Gy were less likely to have ever been pregnant (RR, 0.56 for 5 to 10 Gy; 95% CI, 0.37 to 0.85; RR, 0.18 for $> 10$ Gy; 95% CI, 0.13 to 0.26). Those with a summed alkylating agent dose (AAD) score of three or four or who were treated with lomustine or cyclophosphamide were less likely to have ever been pregnant.	We have demonstrated that fertility is impaired in female childhood cancer survivors, and we have provided treatment-specific and dose-specific risk estimates. Women age 15 to 44 years who received a hypothalamic/pituitary radiation dose greater than 30 Gy; an ovarian/uterine radiation dose greater than 5 Gy; or CCNU, cyclophosphamide, or any AAD summed score of three or four were less likely to ever become pregnant. These data may be utilized to counsel patients and their parents before initiation of treatment and to identify those at exceptionally high risk for impaired fertility who may benefit from assisted reproduction techniques.
<b>(32) Fertility of Male Survivors of Childhood Cancer: A Report From the</b>	This study was undertaken to determine the effect of treatment for	We reviewed the fertility of male Childhood Cancer Survivor Study	The 6,224 survivors age 15 to 44 years	CCS who were not surgically sterile were less likely to sire a pregnancy than siblings (hazard ratio [HR], 0.56; 95% CI, -0.49	This large study identified risk factors for decreased fertility that may be used for counseling male cancer patients.

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
<b>Childhood Cancer Survivor Study</b>  Daniel M. Green, Toana Kawashima, Marilyn Stovall, Wendy Leisenring, Charles A. Sklar, Ann C. Mertens, Sarah S. Donaldson, Julianne Byrne, and Leslie L. Robison (2010)	childhood cancer on male fertility.	survivor and sibling cohorts who completed a questionnaire. We abstracted the chemotherapeutic agents administered, the cumulative dose of drug administered for selected drugs, and the doses and volumes of all radiation therapy from medical records. Risk factors for siring a pregnancy were evaluated using Cox proportional hazards models.		to 0.63). Among survivors, the HR of siring a pregnancy was decreased by radiation therapy of more than 7.5 Gy to the testes (HR, 0.12; 95% CI, -0.02 to 0.64), higher cumulative alkylating agent dose (AAD) score or treatment with cyclophosphamide (third tertile HR, 0.42; 95% CI, -0.31 to 0.57) or procarbazine (second tertile HR, 0.48; 95% CI, -0.26 to 0.87; third tertile HR, 0.17; 95% CI, -0.07 to 0.41). Compared with siblings, the HR for ever siring a pregnancy for survivors who had an AAD score = 0, a hypothalamic/pituitary radiation dose = 0 Gy, and a testes radiation dose = 0 Gy was 0.91 (95% CI, 0.73 to 1.14; $P = .41$ ).	We demonstrated that the fertility of male childhood cancer survivors is impaired. Men age 15 to 44 years, who received a testicular radiation dose of more than 7.5 Gy, were treated with procarbazine or cyclophosphamide, or had a summed alkylating agent dose score of 2, or were less likely to sire a pregnancy. Men diagnosed in early childhood were more likely to sire a pregnancy than those diagnosed in adolescence. These data may be used to counsel patients and their parents before initiation of treatment regarding their future fertility.
<b>(33) A Qualitative Study of the Impact of Cancer on Romantic Relationships, Sexual Relationships, and Fertility: Perspectives of Canadian Adolescents and Parents During and After Treatment</b>	We sought to gain insight into perspectives around core domains of adolescent development—romantic relationships, sexual relationships, and fertility—from the vantage point of Canadian adolescents and parents during and	Using a semi-structured guide, adolescents and parents were interviewed separately. All interviews were audio-recorded and transcribed. Transcribed interview data were independently coded according to the study objectives by two	Twenty adolescents (12–17 years old at interview) and 20 parents (who may or may not have had an adolescent interviewed) participated in this study.	Qualitative analysis revealed main themes for adolescents and parents related to: (1) romantic relationships (opinions on the importance of dating in the context of cancer, expectations that cancer will impact future relationships, dating as a source of moral support, and limited opportunities to engage with partners); (2) sexual relationships (thoughts related to the impact of cancer on	Findings from this study highlight cancer-specific relationship and fertility issues faced by adolescents and provide important direction to the development of interventions that may ultimately improve the psychosocial health of adolescents during and after cancer treatment.

Study, Author, Year	Purpose	Methods	Sample	Findings	Recommendations for further research or practice
Jennifer N. Stinson, Lindsay A. Jibb, Mark Greenberg, Maru Barrera, Stephanie Luca, Meghan E. White, Abha Gupta	after cancer treatment.	trained analysts. Codes were organized into categories that reflected emerging themes. Discrepancies in coding were resolved through discussion with the lead investigator.		future sexual relationships); (3) fertility (initiating treatment as a primary concern and fear of infertility and perceived consequences); and (4) recommendations for care (access to knowledge and support through adolescent-friendly and accessible means).	
<b>(34) Fertility challenges a burden for adolescents and young adults with cancer: new report</b>  The Canadian Partnership Against Cancer (the Partnership)	To explore AYA's experiences	Mixed methods (statistics presented in report, as is data from qualitative interviews)	Adolescents and young adults (AYAs) – aged 15 to 39 – living with cancer	The report identified fertility as a primary concern for men and women in this group, and that the emotional and financial impact of the inability to become biological parents, as a result of cancer treatment, can be devastating to individuals and their families. Loss of fertility as a complication of cancer therapy is important, specifically to adolescents and young adults. Many who survive cancer but find themselves infertile, experience damage to their aspirations and identity, made all the worse if they feel that they weren't made aware of the risks of infertility nor of opportunities to preserve fertility prior to cancer therapy.	Most fertility clinics get very few referrals for AYAs with cancer, suggesting that the majority are not being referred for counselling," said Dr. Anne Katz, Sexuality Counselor at CancerCare Manitoba. "We need to identify gaps in care and steps to be taken to ensure equitable access to fertility preservation counselling and services for young men and women with cancer across the country."



## Appendix B: Consent to Contact Form



THE UNIVERSITY OF BRITISH COLUMBIA

### *PERMISSION TO CONTACT*

#### **Facing the Unknown: Infertility in Young Adult Survivors of a Childhood Cancer**

Dear Patient,

#### **Re: Facing the Unknown: Infertility in Young Adult Survivors of a Childhood Cancer**

We are informing you of a study regarding childhood cancer survivorship and the experience of an unknown fertility status, which is being conducted in affiliation with the University of British Columbia and the Late Effects Assessment & Follow up (LEAF) clinic in BC.

This study is being conducted by Dr. Fuchsia Howard who is an assistant professor at the University of British Columbia with a research focus on cancer survivorship, Dr. Karen Goddard who is the lead oncologist working at the LEAF clinic, Dr. Sally Thorne, a professor at the University of British Columbia, and Kelly Newton, a Master's student conducting this research as her thesis work.

The research team is trying to gain valuable information about childhood cancer survivors' experiences with fertility, so that better guidance, health care practices and fertility resources may be provided for future patients. To provide you with more information about the study or to arrange for your participation **Kelly Newton** would like to contact you via phone or email.

Are you willing to learn more about the “**Facing the Unknown: Infertility in Young Adult Survivors of a Childhood Cancer**” study? (Circle one)

YES

NO

Name: \_\_\_\_\_ Signature: \_\_\_\_\_

Telephone #: \_\_\_\_\_

E-mail: \_\_\_\_\_

Method of contact preferred (circle one):    Telephone    E-mail

Participation in the study is voluntary and you may choose not to participate at any time.

Sincerely,

Kelly Newton

## Appendix C: Participant Demographics

### Characteristic

Gender	Male	Female		
	5	5		
Age	Mean	Range		
	28	19-36		
Race	Caucasian	Asian		
	7	3		
Place of Residence	Vancouver	Burnaby	Kamloops	Maple Ridge
	6	2	1	1
Age of Cancer Onset	Mean	Range		
	8	16-36		
Type of Cancer	Lymphoma	Leukemia	Sarcoma	
	3	6	1	
Cancer Recurrence	Yes	No		
	2	8		

## Appendix D: Demographic Survey

### Facing the Unknown: Infertility in Young Adult Survivors of a Childhood Cancer

#### Demographic Data Form

Date: \_\_\_\_\_

dd/mm/yyyy

ID
----

1. Current age in years: _____ 2. Gender: _____	3. Place of residency: _____
4. Who do you live with? ____ (1) Alone ____ (2) With a partner/husband/wife ____ (3) With my parents ____ (3) With roommates ____ (4) Other _____	5. Do you have siblings? _____ 6. If so, what is their gender and age? _____
7. Level of Education: ____ (1) Elementary school ____ (2) Part of high school ____ (3) High school ____ (4) Part of university/college ____ (5) University/college ____ (6) Graduate school	8. Current Employment Status: (select the best response) ____ (1) Employed full-time ____ (2) Employed part time by choice ____ (3) Employed part-time due to illness ____ (4) Unemployed due to illness ____ (5) Unemployed ____ (7) Homemaker ____ (8) Student ____ (9) Other _____
9. Current occupation? _____ _____	10. Ethnocultural Background: ____ (1) Caucasian

	____ (2) African-Canadian ____ (3) South Asian-Canadian ____ (4) Asian-Canadian ____ (5) Hispanic-Canadian ____ (6) Aboriginal/First Nations ____ (7) Other _____
11. Marital Status: ____ (1) Single/never married ____ (2) Married ____ (3) Divorced/separated	
12. How old were you when you were diagnosed with cancer? _____	
13. What type of cancer were you diagnosed with? _____ _____ _____ _____	
14. What treatments did you receive? _____ _____ _____ _____	

15. Have you been diagnosed with a second or recurrent cancer?

\_\_\_ No

\_\_\_ Yes

If Yes,

How old were you? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What type of cancer were you diagnosed with? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What treatments did you receive? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

16. Please list the health problems you have had since having had cancer:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

17. Have you been diagnosed with or experienced any of the following Late Effects of cancer treatment (Medical problems)?

- \_\_\_ (1) Learning Difficulties or Cognitive Impairment
- \_\_\_ (2) Impaired Growth and Development
- \_\_\_ (3) Bone, Joint and Soft Tissue Problems
- \_\_\_ (4) Vision Problems
- \_\_\_ (5) Hearing Loss
- \_\_\_ (6) Sexual Development or Infertility
- \_\_\_ (7) Heart / Cardiovascular Problems
- \_\_\_ (8) Lung / Respiratory Problems
- \_\_\_ (9) Dental Problems
- \_\_\_ (10) Endocrine (Hormone) System Problems
- \_\_\_ (11) Digestive Problems
- \_\_\_ (12) Second Cancer
- \_\_\_ (13) Depression
- \_\_\_ (14) Other: \_\_\_\_\_

18. Have you done any of the following?

- \_\_\_ (1) Fertility preservation measures (sperm banking, oocyte cryopreservation)
- \_\_\_ (2) Discussed fertility with your oncologist
- \_\_\_ (3) Discussed fertility with your family doctor
- \_\_\_ (4) Discussed fertility with an other health care provider
- \_\_\_ (5) Conducted online research about fertility
- \_\_\_ (6) Undergone medical evaluation to determine your fertility status
- \_\_\_ (7) Undergone fertility treatments
- \_\_\_ (8) Used complementary or alternative treatments for fertility
- \_\_\_ (9) Other: \_\_\_\_\_

## Appendix E: Interview Guide


### Interview Guide:

I'd like to get a picture of the issues you may have experienced regarding your fertility status and how you've managed or dealt with these issues. I would also like to know what it has been like for you to get help to manage or deal with these issues.

1. **How did you come to wonder about your ability to have children?**
  - **When did you start to think about your ability to have children?**
2. Tell me about what you know about your own fertility status, what you think your risks could be?
3. Tell me about your experiences so far related to not knowing whether you are able to have children?
4. Tell me about the discussions you've had with health care professionals related to your fertility.
  - Probe: Which health care professional (i.e. oncologist, psychologist, nurse practitioner, social worker) would you choose to discuss fertility? Why?
5. Tell me about the discussions you've had with your partner/spouse related to your fertility.
  - Probe: how has fertility shaped your romantic relationship(s)?
6. Tell me about the discussions you've had with close friends/family about your fertility.
7. What, if anything, has been challenging for you, related to not knowing your fertility status?
8. What, if anything, has made your experience related to not knowing your fertility status, easier?
9. Tell me about some of the fears you have for your children, or potential children?
10. If you had any recommendations for children undergoing cancer treatment and their parents, what would they be?
11. What information do you think is important for cancer survivors to know about potential infertility?
12. How do you think things might be different for men and women when facing uncertain fertility?
13. Is there anything else that we did not talk about that you might like to add?



## Appendix F: Study Poster



THE UNIVERSITY OF BRITISH COLUMBIA

**FACING THE UNKNOWN: INFERTILITY IN YOUNG ADULT SURVIVORS OF A CHILDHOOD CANCER**

**Are you are a cancer survivor aged 19 to 35 years?**

If so, you may be interested in participating in this UBC study.

**What is the purpose of the study?**

This study will examine the challenge of unknown infertility in both men and women. The findings from this study will help guide health services according to the areas of identified need, support patient-education, and assist in better follow up care.

**What would you need to do?**

Take part in a one-on-one, in-person or telephone interview with a member of the research team.

**How will you benefit from this study?**

Participants will have the opportunity to help guide the development of health services for cancer survivors.

**Will my privacy be protected?**

All personal information will remain confidential.

**Study Ethics Approval** [#H16-01916 ]

**We would greatly benefit from your input. To participate in the study, please contact us:**

Investigators:

Dr. Fuchsia Howard  
Ms. Kelly Newton  
Dr. Karen Goddard  
Dr. Sally Thorne

School of Nursing  
Faculty of Applied Science  
University of British Columbia  
T201 - 2211 Wesbrook Mall  
Vancouver, BC V6T 2B5

**Tel: (604) 822-4372**

**Email: [fuchsia.howard@ubc.ca](mailto:fuchsia.howard@ubc.ca)**

## Appendix G: Consent Form



THE UNIVERSITY OF BRITISH COLUMBIA

**School of Nursing**  
Vancouver Campus  
T201-2211 Wesbrook Mall  
Vancouver, BC Canada V6T 2B5

Phone 604 822 7419  
Fax 604 822 7466  
[www.nursing.ubc.ca](http://www.nursing.ubc.ca)

### Participant Information and Consent Form

#### Facing the Unknown: Infertility in Young Adult Survivors of a Childhood Cancer

**Principal Investigator:** **Dr. Fuchsia Howard, RN, PHD**  
Assistant Professor, UBC Faculty of Applied Science, School of Nursing  
604-822-4372  
Email: [fuchsia.howard@ubc.ca](mailto:fuchsia.howard@ubc.ca)

**Co-Investigator(s):**

Ms. Kelly Newton	MSN/MPH Candidate UBC Faculty of Applied Science, School of Nursing Email: <a href="mailto:kelly.newton@alumni.ubc.ca">kelly.newton@alumni.ubc.ca</a>
Dr. Sally Thorne	Professor UBC Faculty of Applied Science, School of Nursing 604-822-7482
Dr. Karen Goddard	BC Cancer Agency, Radiation Oncology; UBC Faculty of Medicine, Division of Radiation Oncology and Developmental Radiotherapeutics 604-877-6000, ext. 2672

**Sponsors:** This study is being funded by the UBC School of Nursing.

**For emergencies only:** Call the centre nearest you and ask for your study doctor or, if he or she is not available, ask for your usual oncologist or the oncologist on-call.

Vancouver Centre (604) 877-6000

**For non-emergency contact numbers:** 604-822-4372

### 1. Invitation

You are being invited to take part in this research study because you have survived a childhood cancer, have an unknown fertility status, are aged 19 to 35 years, and are currently living in British Columbia.

## **2. Your participation is voluntary**

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences to the medical care, education, or other services to which you are entitled or are presently receiving. Please review the consent document carefully when deciding whether or not you wish to be part of the research and sign this consent only if you accept being a research participant.

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

Please take time to read the following information carefully and to discuss it with your family, friends, and doctor before you decide.

## **3. Who is conducting this study?**

This study is being conducted by the University of British Columbia and the BC Cancer Agency. This study is not receiving any funds from an external agency or sponsor.

## **4. Background**

Now that the majority of children diagnosed with cancer will survive, there is a need for health care professionals to become better adept in the education and management of long-term and new treatment-related health problems. Infertility can be a particularly devastating outcome for childhood cancer survivors, because it has the potential to influence important life choices and alter interpersonal relationships.

## **5. What is the purpose of the study?**

The purpose of this study is to identify the challenges that childhood cancer survivors face related to unknown infertility status. The findings from this study will help guide health services according to the areas of identified need, support patient-education, and assist in better follow up care.

It is hoped that by carrying out this study, the experiences of the participants will help the researchers examine the needs of childhood cancer survivors as they face the possibility of being infertile. With this knowledge, follow-up practices can be better directed.

This research is being completed as part of a thesis project that is a requirement for Ms. Kelly Newton's master's program in Nursing.

## **6. Who can participate in this study?**

You may be able to participate in this study if you:

- Had a childhood cancer (cancer occurring before the age of 18)
- Are currently aged 19-35
- Have not had cancer treatments in the last two years
- Have an unknown fertility status

## **7. Who should not participate in this study?**

You will not be eligible to participate in this study if:

- You have a confirmed fertility status (you know you are fertile, or you know you are infertile)
- You have had cancer treatment within the last two years

## **8. What does the study involve?**

If you agree to take part in this study, you will take part in a telephone interview with one of the researchers. During this interview, you will be asked about your experiences of being a cancer survivor and challenges related to your fertility status. Questions will also be asked about the challenges you face in getting fertility-related medical care and the factors that have contributed to these challenges. The interview will last up to one hour, will occur at a date and time of your choice, will be audio recorded, and later transcribed verbatim. You will also be asked demographic questions at the conclusion of the interview.

### **Study Phone Call**

You will participate in 1 phone call for this study, lasting roughly 45-60 minutes.

#### **1.1 Expected Follow-up**

1.2 There are no expected follow up phone calls for this study.

## **9. What are my responsibilities?**

Participate in an interview lasting 45-60 minutes, answering questions to the best of your ability

## **10. What are the possible harms and discomforts?**

There are no expected risks (problems) related to taking part in this study. Because this may be a sensitive topic for you to discuss, however, participation in this study may bring about strong emotions. Should this occur, we will ensure there are appropriate resources made available to help you. Your decision whether or not to take part in this research will not influence the health care you receive.

### **11. What are the potential benefits of participating?**

No one knows whether or not you will benefit from this study. There may or may not be direct benefits to you from taking part in this study.

We hope that the information learned from this study can be used in the future to benefit other childhood cancer survivors.

### **12. What happens if I decide to withdraw my consent to participate?**

You may withdraw from this study at any time without giving reasons. If you choose to enter the study and then decide to withdraw at a later time, you have the right to request the withdrawal of your information collected during the study. This request will be respected to the extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn for example where the data is no longer identifiable (meaning it cannot be linked in any way back to your identity) or where the data has been merged with other data. If you would like to request the withdrawal of your data, please let your study researcher know. If your participation in this study includes enrolling in any optional studies, or long term follow-up, you will be asked whether you wish to withdraw from these as well.

### **13. How will my taking part in this study be kept confidential?**

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

You will be assigned a unique study code number as a participant in this study. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, SIN, or your initials, etc.). Only this number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique

study number that is used on your research-related information will not be removed or released without your consent unless required by law.

All documents will be identified only by code number and kept in a locked filing cabinet in Dr. Fuchsia Howard's office or as password-protected computer files on the encrypted network of the UBC School of Nursing. Paper documents (e.g., consent forms) and electronic audio files will be kept for 5 years after the results are presented or published and then these will be destroyed by shredding paper files and deleting digital files. Only the research team will have access to the data collected in this study. Your name and any identifying information will not appear in any reports of the completed study. Information disclosing your identity will not be released or published. Findings from the study may be shared through conference presentations, articles for publication, and other media outlets or used for teaching purposes without revealing any information that would identify you. Findings will not be reported back directly to participants; however, a summary of the research findings will be available to you on request.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected. You also have the legal right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information.

### **Disclosure of Race/Ethnicity**

Studies involving humans now routinely collect information on race and ethnic origin as well as other characteristics of individuals because these characteristics may influence how people respond to different medications. Providing information on your race or ethnic origin is voluntary.

## **14. What will the study cost me?**

All research-related costs during your participation in this study will be covered by the researchers.

### **Remuneration**

You will be offered \$20.00 for your participation in this study.

## **15. Who do I contact if I have questions about the study during my participation?**

If you have any questions or desire further information about this study before or during participation, or if you experience any adverse effects, you can contact Dr. Fuchsia Howard (PI) or Ms. Kelly Newton at [kelly.newton@alumni.ubc.ca](mailto:kelly.newton@alumni.ubc.ca)

## 16. Who do I contact if I have any questions or concerns about my rights as a participant?

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

## 17. Signatures

Facing the Unknown: Infertility in Young Adult Survivors of a Childhood Cancer

### Participant Consent

My signature on this consent form means:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.

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

I consent to participate in this study.

Participant's Signature	Printed name	Date	
Signature of Person Obtaining Consent	Printed name	Study Role	Date

If this consent process has been done in a language other than that on this written form, with the assistance of an interpreter/translator, indicate:

Language: \_\_\_\_\_

Was the participant assisted during the consent process in one of ways listed below?

☐ Yes ☐ No [Note: For typical situations where the person conducting the consent discussion simply reads the consent with the participant to ensure that informed consent is properly obtained, check “no”.]

If yes, please check the relevant box and complete the signature space below:

☐ The consent form was read to the participant, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant (please check if participant is unable to read).

☐ The person signing below acted as an interpreter/translator for the participant, during the consent process (please check if an interpreter/translator assisted during the consent process).

\_\_\_\_\_  
Signature of Person Assisting  
in the Consent Discussion

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date

**Investigator Signature**

\_\_\_\_\_  
Investigator Signature

\_\_\_\_\_  
Printed name

\_\_\_\_\_  
Date

My signature above signifies that the study has been reviewed with the study participant by me and/or by my delegated staff. My signature may have been added at a later date, as I may not have been present at the time the participant’s signature was obtained.



## Appendix H: Fertility Information Pamphlet for Cancer Survivors in BC

### Fertility After Cancer *A resource for cancer survivors in BC* 2017

#### About this resource

This information sheet was produced for individuals who are living with an unknown fertility status after surviving some form of cancer. The content included in this resource is based upon the information needs expressed by young adult survivors of a childhood cancer during a qualitative study. This study, which involved 5 men and 5 women, was conducted in conjunction with the University of British Columbia. It is hoped that this resource can assist in addressing unanswered questions, and offer critical resources for cancer survivors seeking fertility-related help.

#### General Facts

##### Risk of infertility among cancer survivors

Cancer treatments, including some chemotherapeutics, radiation therapy, and surgery, might cause infertility, which can be temporary or permanent. Your risk of infertility will depend on the specific treatments you received. If you are concerned, it is best to speak with your health care provider so that they can evaluate your personal risk.

#### Male Survivors & Fertility

Male infertility is an inability to produce healthy sperm or to ejaculate sperm.

Fertility testing includes collecting a sperm sample and measuring it under a microscope. Sperm count (the number of sperm present), motility (percentage of sperm actively swimming) and morphology (shape of the sperm) is looked at.

#### Female Survivors & Fertility

Fertility issues in women are caused by various dysfunctions of reproductive organs and systems. For a woman to successfully conceive and deliver, the following components are important:

- A normal menstrual cycle
- Follicle stimulating hormone (FSH)
- Hormone development
- Undamaged and unobstructed fallopian tubes
- A uterus capable of supporting a developing fetus

All of these factors contribute to increased fertility. If your body is having trouble with one of these, medical intervention can help.

#### Fertility Clinics in BC

There are multiple fertility clinics in BC that offer specialized fertility services.

##### Olive Fertility Centre

555 East Tower 12th Ave Suite 300 Vancouver, British Columbia V5Z 3X7  
604-559-9950  
[info@olivefertility.com](mailto:info@olivefertility.com)  
<http://www.olivefertility.com/>

##### Genesis Fertility Centre

300-1367 West Broadway, Vancouver, British Columbia, V6H 4A7  
604-879-3032  
[genesis@genesis-fertility.com](mailto:genesis@genesis-fertility.com)  
<http://genesis-fertility.com>

##### Grace Fertility Centre

#201-604 West Broadway, Vancouver  
604-558-4886  
<http://fertilitywithgrace.com>

##### Kelowna Regional Fertility Centre

202-1630 Pandosy Street,  
Kelowna, BC V1Y 1P7  
Phone: 250-861-6811 or Toll-free 1888-861-5732 Fax  
250-861-6814  
[www.kelownafertility.ca](http://www.kelownafertility.ca)  
[info@krfc.ca](mailto:info@krfc.ca)

##### Pacific Centre for Reproductive Medicine (offices in Burnaby, Surrey and Vancouver)

#500 - 4601 Canada Way, Burnaby (main office)  
Phone: 604-422-7276 or Toll-free 1866-481-7276 Fax  
604-434-5522  
<http://pacificfertility.ca/>

##### Victoria Fertility Centre

#207 - 4400 Chatterton Way,  
Victoria British Columbia, Canada V8X 5J2  
Phone: 250-704-0024 or Toll Free: 1888-704-2229  
Fax: 250-704-0034  
[www.victoriafertility.com/](http://www.victoriafertility.com/)  
[inform@victoriafertility.com](mailto:inform@victoriafertility.com)

## Alternate options...

### Adoption

#### **Sunrise Adoption Agency**

171 W Esplanade #102  
North Vancouver, BC V7M 3J9  
1.888.984.2488  
<http://www.sunriseadoption.com>

#### **AFABC - Adoptive Families of BC**

1-877-236-7807  
<https://www.bcadoption.com>  
[info@bcadoption.com](mailto:info@bcadoption.com)

#### **Choices Adoption & Pregnancy Counselling**

100-850 Blanchard St. Victoria BC, V8W 2H2  
1-888-479-9811  
[choices@choicesadoption.ca](mailto:choices@choicesadoption.ca)  
<http://www.choicesadoption.ca/about-us/>

#### **FSGV- Family Services Adoption Agency**

301-1638 East Broadway, Vancouver BC, V5N1W1  
604-736-7613  
<http://www.fsgvadoptionagency.ca>

### **Artificial insemination by husband's/partner's cryopreserved semen**

Artificial insemination using husband's/partner's (AIH) cryopreserved semen is a widely available technique. Where adequate quantities of sperm have been banked, they are injected into the cervix or uterus at the time of ovulation.

### **Donor insemination**

Donor insemination is widely available and may be considered for women whose husband/partner faces fertility issues from treatment and where preserved sperm are unavailable. Sperm is provided by donors who are usually matched for racial and physical characteristics.

### **IVF/ICSI**

Where only small quantities of preserved sperm are available (as will commonly be the case), IVF/ICSI may be considered. ICSI involves injection of a single sperm into each oocyte. Pregnancy results are generally favourable (28% for women under 35 years of age). One possible risk when using this method is associated with multiple pregnancy, especially from pre-term delivery.

### **Egg donation**

In women whose ovarian reserve has been severely depleted (eg. by chemotherapy) or who are undergoing or have completed menopause, egg

## • **Mental Health Services & Support Groups**

- Fertile Future - Canadian non-profit organization that provides fertility preservation information and support services  
<http://fertilefuture.ca/>

- Fertility Matters Canada (FMC) - the national organization that empowers Canadians to help reach their reproductive health goals by providing support, awareness, information and education.  
<http://fertilitymatters.ca/#>

- Cancer Hope Network - matches you with another cancer survivor for support from someone who's "been there"  
<http://support.cancerhopenetwork.org/>

## • **Health of Biological Children**

**"There is currently no evidence that cancer treatments increase the incidence of birth defects in children conceived after treatment has been completed.** It is generally recommended, however, that male or female patients delay starting a family for a minimum of one year after cancer treatment, mainly because of concern about relapse, but also because of the possible mutagenic effects of treatment on the gametes." - Royal College of Obstetricians and Gynaecologists, 2007

## **Other resources:**

More information can be found at the following websites:

<https://www.livestrong.org/we-can-help/livestrong-fertility>

<http://www.uptodate.com/contents/overview-of-infertility-and-pregnancy-outcome-in-cancer-survivors>

<http://stupidcancer.org>

<https://www.cancercare.org/tagged/fertility>

**For information on cost-savings from referrals, please visit:**

<http://www.bccancer.bc.ca/coping-and-support-site/Documents/Fertility%20Preservation%20Resources%20for%20Cancer%20Patients.pdf>