The Views of Adolescent and Young Adult Cancer Survivors Regarding Their Fertility and Fertility Preservation

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THE VIEWS OF FEMALE ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS REGARDING THEIR FERTILITY AND FERTILITY PRESERVATION

By
Katherine Hauck Perez

A DISSERTATION

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of the University of Miami
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THE VIEWS OF FEMALE ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS REGARDING THEIR FERTILITY AND FERTILITY PRESERVATION

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Female Adolescent and Young Adult (AYA) cancer survivors often face potential fertility impairment due to cancer treatment. The purpose of this dissertation was to explore the experiences of female AYA cancer survivors regarding fertility preservation (FP) during the early stage of cancer diagnosis and treatment, a critical time for FP decision-making, and their experience regarding fertility during the survivorship stage. To date The Model for Care Across the Cancer Continuum (Hudson, 2005) has not been used in the context of fertility and FP. The model suggests there are three types of care an individual diagnosed with cancer transitions through, cancer diagnosis, long-term survival and survivor health and resilience. The Model for Care Across the Cancer Continuum was chosen as the framework for this study because fertility and fertility preservation are relevant throughout the cancer trajectory suggested by the model and allow the results of this study to inform clinical practice and policy and ultimately, improve care across the cancer continuum for AYA cancer survivors. Semi-structured interviews focused on the fertility and FP experience of eighteen women aged 21-39 in-person or via Skype or Facetime.
A qualitative approach using descriptive design and thematic analysis was used to explore the views of AYA cancer survivors regarding their fertility, their experiences regarding FP, and the impact FP has had on their lives thus far. Four themes emerged from young women cancer survivors’ experiences with fertility and fertility preservation: 1) Unpredictability of Life, 2) Loss: The Toughest Pill to Swallow, 3) Relationships: Struggling to Meet Societal and Familial Expectations, and 4) Moving on with Life. Although the focus of this dissertation was fertility and fertility preservation, other salient issues such as hair loss, sexual health, and transitioning from independence to dependence and re-integration to work or school were frequently discussed.

The findings from this dissertation suggest fertility and FP is an important piece of the AYA cancer care continuum and has implications at various points across the care continuum for AYAs and their healthcare providers. Accounts of uncertainty, loss, grief, and envy were frequently discussed and impacted relationships with family and friends. Support from family, friends and faith positively impacted their fertility experiences. The implications from these accounts suggest improving access to resources and mental health support are important and impactful on the fertility and FP experience. These findings inform researchers and clinicians as they work to improve care across the cancer continuum, specifically FP discussions at cancer diagnosis, FP decisions before and after cancer treatment, and managing fertility after cancer treatment.
Dedication
This dissertation is dedicated to adolescents and young adult women diagnosed with cancer that must make a fertility preservation decision. You are incredibly strong, resilient women.
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• The Graduate School and Faculty
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CHAPTER 1

Introduction

Problem

For many years, clinical and research agendas have focused solely on improving cancer survival. This focus on survival has led to medical technology improvements and allowed millions of people diagnosed with cancer to become survivors. These survivors continue to live longer, healthier, and fulfilled lives (ACS, 2014). Treatment advances have shifted some of the clinical focus in cancer to more long-term health and quality of life issues (Quinn et al., 2007; Vadaparampil, Quinn, King, Wilson & Nieder, 2008). With a general increase in survival, survivorship care becomes of increasing clinical and research interest.

Each year in the United States, approximately 70,000 adolescents and young adults (AYA) are diagnosed with cancer. For patients diagnosed with cancer during this period, treatment effects on the reproductive system impact the emotional, psychological and social well-being of survivors and affects survivors’ quality of life (IOM, 2011). AYAs diagnosed with cancer present with a unique and challenging set of issues because of the many physical, psychological and interpersonal changes associated with the normal maturation process (Crawshaw, Glaser, Hale & Sloper, 2009; Lewis et al., 2013). Establishing committed relationships, the growing importance of social relationships, increasing autonomy from the family, body image, and self-esteem are important aspects of AYA development that intersect with cancer and with issues of infertility. Plans for the future pertaining to education, careers and family begin to take shape but are suspended by the cancer diagnosis. Much of the normal maturation process is disrupted by the
physical, psychological and interpersonal changes that occur with cancer and cancer treatment.

The Institute of Medicine (IOM) 2006 report on Cancer Survivorship Care Planning emphasized the necessity of long-term survivorship care plans, especially long-term effects of cancer treatment on the reproductive system. Certain cancer treatment regimens have the potential to impair fertility and have implications for the well-being of patients at risk for fertility impairment. Women with uncertain fertility and diagnosed infertility can experience serious long-term psychological problems including difficulty building and maintaining intimate relationships, problems in communication with family and friends, and issues related to social identity (ACS, 2013; Tschudin & Bitzer, 2009).

Fertility preservation (FP) technologies are now available for oncology patients. Clinicians, now more than ever due to an increase in cancer survivorship, have been faced with educating and counseling patients about the possibility of fertility impairment related to cancer treatment and FP options. In an effort to ensure all cancer patients of reproductive age have the option of FP, the American Society of Clinical Oncology (ASCO) published FP guidelines for healthcare providers in June 2006. These guidelines recommend that healthcare providers treating cancer patients, including pediatric patients, address the possibility of infertility related to cancer treatment and discuss FP options as early as possible so a referral can be made to a reproductive specialist early in the treatment process (Lee et al., 2006). However, FP is one of the most under-prescribed and least implemented services for AYA cancer patients (Coccia et al., 2014). AYA cancer patients may experience long-term effects related to a lack of prescribed and available FP resources.
Background of the Problem

Specific cancer treatments such as radiation, certain chemotherapy drugs, and surgery can increase the risk for infertility. The extent of reproductive impairment is dependent on the drug given, the dose received, the age during treatment, and the gender of the patient (Zakak, 2009). The most common cancers in the AYA population are lymphoma, leukemia, germ cell tumors (including testicular cancer), melanoma, central nervous system tumors, sarcomas (bone and soft tissue), and breast, cervical, thyroid and colorectal cancers (National Cancer Institute, 2015). Treatments for many of the most common cancers in AYAs have a detrimental effect on fertility.

Guidelines from ASCO consider sperm and embryo cryopreservation the standard practice option for males and oocyte cryopreservation, embryo cryopreservation and ovarian transposition the established options for females (Loren et al., 2013). In addition to the established options, there are experimental options available for females including ovarian tissue cryopreservation. (Lobo, 2005; Nisker, Baylis, & McLeod, 2006). For younger AYAs and women without a partner, embryo cryopreservation is usually not a feasible option because embryo cryopreservation requires sperm to fertilize the egg before it is frozen. In comparison to sperm collection for cryopreservation in males, oocyte retrieval for cryopreservation in females requires ovarian stimulation which could delay treatment and requires a medically invasive procedure to harvest the oocytes. The focus of the proposed dissertation is FP among females for whom the established and experimental options could take several weeks to be performed due to the complexity of the procedures and may require a delay in cancer treatment.
Significance

The importance of FP among female cancer survivors has received much attention in recent years in an effort to provide the best care to these individuals and support them in transitioning back to life after cancer. Uncertain fertility and infertility affects the psychosocial well-being of female adult cancer survivors, and perceived infertility can have a detrimental effect on the psychosocial health of cancer survivors. Similar to female adult cancer survivors, two retrospective studies on survivors of childhood cancer who experienced or suspected a loss of fertility suggest negative effects on their psychosocial well-being (Crawshaw & Sloper, 2006; Zebrack et al, 2004). Healthcare providers agree that treatment-related fertility risks, FP discussions and FP options are important for AYA cancer patients and an essential part of their care (Levine, Canada, & Stern, 2010; King et al, 2008). However, healthcare providers do not consistently discuss FP with patients. Research has documented various reasons healthcare providers are not consistent in discussing FP such as lack of knowledge, lack of training, attitudes toward FP, delay of treatment, and financial costs (Levine, Canada, & Stern, 2010; Quinn & Vadaparampil, 2009; King et al, 2008). Much of the research on cancer survivors and FP, the majority of which has been with adult cancer survivors, focuses on communication between the patient and provider, barriers to communication about FP from the provider perspective, and patient attitudes toward FP. Research with young adult and adult cancer survivors suggest difficulty with decision making about FP (Corney & Swinglehurst, 2013; Kirkman et al., 2012).
Purpose and Aims

The purpose of this dissertation was to explore the experiences of female AYA cancer survivors regarding FP during the early stage of cancer diagnosis and treatment, a critical time for FP decision-making, and their experience regarding fertility during the survivorship stage. This research contributes knowledge specific to the FP experience of AYA cancer survivors, the satisfaction of AYA’s with the FP decision, the impact of FP on their lives, and how their experiences can inform clinicians and future patients experiencing a FP decision. The study gained participants retrospective reflections regarding the FP experience after the cancer diagnosis and therefore, may inform clinicians and researchers about issues that arise over time after the participants were able to process the FP experience. These findings inform researchers and clinicians as they work to improve care across the cancer continuum, specifically FP discussions at cancer diagnosis, FP decisions before and after cancer treatment, and managing fertility after cancer treatment.

A qualitative approach using descriptive design and thematic analysis was used to explore the views of AYA cancer survivors regarding their fertility, their experiences regarding FP, and the impact FP has had on their lives thus far. The purpose was accomplished through three aims:

Aim 1

Describe the views female AYA cancer survivors have toward their fertility and FP decisions.
Aim 2

Describe the impact fertility and FP decisions had on their lives and their satisfaction with the FP decision and process.

Aim 3

Identify areas for improvement regarding FP across the cancer continuum as described by survivors of AYA cancers.
Chapter 2

Literature Review

AYAs Defined

Adolescent and young adult (AYA) cancer patients are defined as individuals 15 to 39 years of age at the time of diagnosis. The age limits of AYAs with cancer were established by the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG) in the report, Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer (2006), based on physiological and psychosocial needs of this group and to “facilitate clarity, consensus, and data collection and comparison” (pg. 3). This age range encompasses puberty through physiological maturity and ends before hormonal and immune response decline (AYAO PRG, 2006). The age range of 15 through 39 years at cancer diagnosis was determined “since the entire age range continues to experience a relative lack of improvement in survival and because a chief concern of AYAs with cancer is the lack of a home in research and healthcare” (pg. 3).

Adolescent and Young Adult Cancer Prevalence

The incidence of specific cancer type varies across the AYA population. The most common cancers in AYAs are lymphoma, leukemia, germ cell tumors (including testicular cancer), melanoma, central nervous system tumors, sarcomas (bone and soft tissue), and breast, cervical, thyroid and colorectal cancers (National Cancer Institute, 2015). These types of cancer account for 86% of cancers in this population (Adolescent and Young Adult Oncology Progress Review Group, 2006). Cancer types vary across the AYA age continuum. Lymphomas, germ cell tumors, and leukemias are the most
common cancers in AYAs aged 15 to 19. Carcinomas, especially breast cancer, are more common in AYAs aged 20 to 39.

**Impact of Cancer Treatment during Adolescence and Young Adulthood on Fertility**

Cancer treatment can potentially have a deleterious effect on fertility. The impact cancer treatment has on fertility is dependent on the drug given, the cumulative dose received, the duration of treatment, the age during treatment, the gender of the patient, and pre-treatment fertility status (Levine, Canada, & Stern, 2010; Zakak, 2009).

The common cancers in AYA females, the focus of this dissertation, include Hodgkin’s lymphoma, thyroid carcinoma, brain and CNS cancers, leukemia, and bone tumors. Treatments for these types of cancer require chemotherapy or radiation regimens that can have a detrimental effect on fertility. Chemotherapy drugs affect ovarian cells by preventing cell division and adversely affecting DNA function (Levine, Canada, & Stern, 2010). Treatment regimens with alkylating agents and heavy metals are more toxic to reproductive organs than other chemotherapy drugs. High doses of alkylating drugs such as cyclophosphamide, ifosfamide, chlorambucil, and melphalan, are more common in treating Hodgkin’s lymphoma, leukemia, brain and CNS tumors, and bone tumors than other cancers. Radiation to the abdomen, pelvis, lower spine, head or brain, or whole body, may also impair fertility. Abdominal and pelvic irradiation, which might be used to treat CNS cancer, may cause permanent damage to the ovaries. Radiation involving the head or brain can affect hypothalamic pituitary function causing hypogonadism or diminished functional activity of the reproductive organs (Levine, Canada, & Stern, 2010). Whole body irradiation, commonly used in treating Hodgkin’s lymphoma, bone
tumors, and CNS tumors, may impair uterine growth and blood flow in females (Critchley, Bath, & Wallace, 2002).

Post-cancer fertility is difficult to accurately predict and little data is available regarding fertility rates of AYAs post-cancer treatment. The National Cancer Institute’s Childhood Cancer Survivor Study has retrospectively studied the long-term effects of cancer treatment on two cohorts of children and AYA that were under 21 years of age at the time of diagnosis: one cohort of children and AYA (and their siblings) diagnosed with cancer between 1970 and 1986, and the second cohort of children and AYA (and siblings) diagnosed with cancer between 1987 and 1999. Recent publications from the Childhood Cancer Survivor Study have documented the reduced fertility of female survivors of childhood cancer (less than 21 years of age at the time of diagnosis). Using data from the Childhood Cancer Survivor Study, including 3,531 female cancer survivors and 1,366 female sibling controls, Barton et al. (2013) found that survivors of childhood cancer had a 48% higher risk of clinical infertility (>1 year of attempts at conception without pregnancy) than their siblings. This study found that higher doses of alkylating agents during chemotherapy and uterine radiation were associated with infertility. In another study using data from the Childhood Cancer Survivor Study, which included 5,149 females who were at least 5 years since the cancer diagnosis and a control group of 1,441 randomly selected siblings, childhood cancer survivors had 81% of the reproductive capacity of their female siblings, after adjustment for age, marital status, and highest level of education achieved (Green et al., 2009).
Fertility Preservation

Fertility preservation (FP) technologies are available for cancer patients, including AYA. FP for females is relatively complex, costly and has greater potential for delaying cancer treatment, than FP for males, which essentially requires storage of sperm cells. The established FP options for females are oocyte and embryo cryopreservation and ovarian transposition (Loren et al., 2013). Embryo and oocyte cryopreservation requires medication that stimulates the ovaries to produce oocytes before cancer treatment is initiated. Ovarian stimulation can take as long as 6 weeks, depending on the menstrual cycle. Ovarian stimulation requires the use of hormones for 10-14 days at the beginning of the menstrual cycle to stimulate the ovaries to produce more mature oocytes. A minor surgical procedure harvests the mature oocytes and they are cryopreserved for oocyte cryopreservation or the oocyte is fertilized by sperm to create an embryo and then cryopreserved. Ovarian transposition or oophoropexy is the relocation of the ovary or ovaries outside of the radiation field before the initiation of treatment. This method does not protect the ovaries from the effects of chemotherapy.

Embryo cryopreservation involving in vitro fertilization is an established and highly successful infertility treatment for women under the age of 40 (Levine, Canada, & Stern, 2010). Cycles of IVF using cryopreserved embryos resulted in delivery rates of approximately 33% (CDC, 2009). A study performed by New York University fertility center found that women utilizing frozen oocytes were able to achieve pregnancy rates of 57% (Grifo et al, 2010). However, success rates of FP for women in the context of cancer are not established (Anderson & Wallace, 2011). Because embryo cryopreservation involves fertilization of the oocyte by sperm through in vitro
fertilization followed by cryopreservation and storage, it is typically only used by women who already have a partner with whom they plan to have a child, and thus is typically not an option for AYA’s except at the upper end of the age range.

In addition to oocyte and embryo cryopreservation, experimental options are available for females including ovarian tissue cryopreservation (Lobo, 2005; Nisker, Baylis, & McLeod, 2005) and hormone suppression. Ovarian tissue cryopreservation requires removal of tissue from an ovary laproscopically and later reimplanting the tissue to restore hormonal function or fertility (Loren et al., 2013). Hormone suppression using gonadotropin-releasing hormone analogs (GnRHa) is believed to put the ovaries in a prepubertal state by stopping ovulation and preserving the oocytes in the ovaries (Levine, Canada, & Stern, 2010). However, evidence supporting this is lacking and is not acknowledged as an effective method of FP by ASCO (Loren et al., 2013).

Only one study was found that examined the uptake and success rates of FP among female cancer survivors, including AYA’s. Lewis and colleagues (2014) conducted a study with 22 women, aged 22-43, who were diagnosed with primary breast cancer between January 2006 and June 2011. In this sample, 13 (59%) used FP (either embryo or oocyte preservation), and of the 22 women, 4 had gotten pregnant; 2 of them through FP (Lewis, Silva, Quinn, Lee, 2014).

American Society of Clinical Oncology (ASCO) Guidelines for FP

In 2006, the American Society of Clinical Oncology (ASCO) published guidelines on FP for patients with cancer and offered healthcare providers multiple recommendations to update clinical oncology practice. The recommendations highlighted the importance of discussing the possibility of infertility as early as possible in the cancer
treatment process. Healthcare providers should also be prepared to discuss FP options and/or refer the patients to reproductive specialist. The guidelines recommend that the FP discussion should be documented by healthcare providers in the patient’s medical record. The guidelines also evaluated the evidence supporting FP options for males and females so healthcare providers would be better informed of standard practice FP options and investigational FP options.

In addition to the recommendations highlighted above, ASCO included special considerations for children and adolescents with cancer based on several studies of adult survivors of childhood cancer that showed survivors wanted more information and options about FP at the time of diagnosis, they were uncertain about their fertility status, and felt regret about not having pursued an FP option (Loren et al., 2013). For post pubertal minor children, the ASCO guidelines recommend that established methods of FP should be used with patient assent, if applicable, and parent or guardian consent. Healthcare providers should communicate that additional methods are available for children but are still considered investigational. Lastly, healthcare providers should refer eligible patients for experimental protocols when available.

The Children’s Oncology Group developed long-term follow-up guidelines for female survivors of childhood, adolescent, and young adult cancer because of the complexity of assessing female fertility status (Metzger et al., 2013). These evidence-based guidelines are specifically focused on screening for female reproductive health as a late effect of cancer treatment. Frequent and early assessment of female reproductive complications after cancer treatment in AYA is recommended to further improve survivor health and quality of life (Metzger et al., 2013). Assessing fertility after cancer
treatment in females requires long-term follow up to monitor ovarian damage and to determine whether damage is temporary or permanent. The resumption of normal menses and menstrual history is not a reliable indicator of fertility. Identifying the presence of follicles is important to determine if immature eggs exist in the ovaries, endocrine assessments need to be performed to determine if hormones are within normal parameters, and assessment of reproductive organs such as the ovaries and uterus are also needed. This testing is usually not performed until a woman tries to conceive. Thus, female survivors of cancer often live with uncertainty regarding their fertility.

Even though the ASCO guidelines were established in 2006, they are not widely adhered to among oncologists. Two years after the guidelines were established, Quinn et al. (2008) conducted a nationwide study with 516 oncologists to determine oncologists’ referral patterns for FP. Of the 516 oncologists, 241 (47%) reported often or always referring patients to an infertility specialist. However, 53% of oncologists reported not referring patients to a specialist. A nationwide survey of pediatric oncologists in 2011 asked oncologists if they were aware of the ASCO guidelines for FP and if they use the guidelines as an aid for decision making with their patients (Kohler et al., 2011). The results showed 44% of the pediatric oncologists were familiar with the ASCO guidelines and 39% used the guidelines in decision making. Kohler et al. (2011) also found that 73% of pediatric oncologists agreed pubertal female patients should be referred to a FP specialist before cancer treatment, but only 23% consistently made a referral.
Barriers to FP

Healthcare Providers Communication Barriers

Studies of health care professionals suggest that discussion of risks for infertility and options for FP are not routinely performed, even when the importance of doing so is recognized (King et al, 2007; Levine, Canada, & Stern, 2010). Some survivors of cancer do not recall receiving information at diagnosis from their healthcare providers about the risks of cancer treatment to fertility. A qualitative study of survivors of adolescent cancer (ages 13 to 18) reported survivors were more likely to recall discussions of possible infertility after initiation of treatment, not at diagnosis (Nieman, et al, 2007). It is possible that some of the patients who do not recall receiving information on infertility at diagnosis were in fact informed, but news of potential infertility was lost among the overwhelming nature and amount of information received at diagnosis (Burns, Boudreau, Panepinto, 2006; Zebrack, Casillas, Nohr, Adams & Zeltzer, 2004). Barriers to FP discussions identified by healthcare providers include lack of time, lack of information regarding FP methods and costs, lack of resources regarding specialists and banking facilities, lack of training, and attitudes toward FP options (King et al, 2007; Levine, Canada, & Stern, 2010; Quinn & Vadaparampil, 2009).

Delay of Treatment

The established FP options available to females require the FP process to be completed before the initiation of cancer treatment. In many cases this process requires that cancer treatment be delayed. Pursuing FP may require a 2 to 6-week delay in treatment for female patients if the established options of FP are pursued due to the requirement of ovarian stimulation. For aggressive cancers, healthcare providers,
families, and AYAs must weigh the risks and benefits of beginning treatment quickly or postponing treatment to pursue FP. Most healthcare providers, families, and AYAs are not comfortable delaying treatment for that amount of time and would rather revisit fertility options after treatment is completed. A study of 50 female adolescents (ages 12-18) and their parents at a pediatric oncology clinic assessed their attitudes regarding FP. Ninety-three percent of parents and eighty percent of adolescents reported they were interested in FP options but were not willing to delay treatment to pursue FP (Burns, Boudreau, & Panepinto, 2006). Most patients want to know what FP options are available so they have the ability to make a decision to delay treatment and pursue FP or to not pursue FP.

How patients feel about whether to delay treatment for FP purposes may change over the course of their cancer history. When Burns et al. (2006) compared adolescents (ages 12-18) still undergoing cancer treatment with adolescents who had completed cancer treatment, a greater proportion of the adolescents who had completed cancer treatment stated they would have been willing to postpone cancer treatment one or more months to pursue FP. A qualitative study of 19 childless women under the age of 45 with breast cancer in the United Kingdom found that two of the women reported that they regretted not pursuing FP; among the seven women who did pursue FP, none regretted that decision (Corney & Swinglehurst, 2014).

Financial Costs

Pursuing FP can be very costly and families of patients who have completed cancer treatment experience significant financial loss due to expenses related to cancer treatments (ACS, 2011). Physicians have consistently indicated cost as one of the main
barriers to pursuing FP (Levine, Canada, & Stern, 2010; Quinn & Vadaparampil, 2009; King et al, 2007). Quinn and Vadaparampil (2009) conducted qualitative interviews with oncologists and found that physicians reported the cost of FP as a barrier because insurance does not cover FP and many families are not able to afford the additional expense. Insurance coverage for FP in patients diagnosed with cancer varies by insurance policy and state, and in many cases FP is not covered by insurance. Dependent AYAs rely on family to help with costs associated with not only FP, but other costs associated with the cancer diagnosis. Financially independent AYAs may experience extreme financial challenges associated with cancer and forego FP because of the added expense. Due to the financial burden FP may place on AYAs and their families, programs such as FertileHope have been established to provide financial assistance for banking at discounted rates with specific banking facilities across the country to help defray the costs associated with FP.

**FP in the Context of Adolescent and Young Adult Cancer**

AYAs with cancer experience unique developmental challenges. They are different from adult cancer patients due to their developmental stage, and they are different from their age peers due to having cancer. Adolescence and young adulthood is a difficult period for FP decision-making because in addition to the challenges of a cancer diagnosis, AYAs are experiencing a stage of life that includes physical, psychological and interpersonal changes that may leave them ill-prepared for this additional task of making a decision about FP. Across the AYA age continuum, developmental stage and maturity can vary widely. For example, the experiences and needs of a 16 year-old high school student, a 21 year-old away at college and a 32 year-old married mother of three
children are very different. Furthermore, the individual’s experiences and needs related to their developmental stage and maturity may not parallel their age, such as when the college student needs to move back home due to the cancer diagnosis. For AYA diagnosed with cancer, the normal maturation process is disrupted and presents AYA with a complex set of physical and psychosocial issues (Crawshaw, Glaser, Hale, & Sloper, 2009; Lewis et al., 2013).

**Physical Issues**

For younger AYA females, puberty causes pronounced physical changes such as menarche, the development of breasts, growth of pubic and underarm hair, changes to the reproductive organs, enlargement of the hips and buttocks, and an increase in height. These changes mark the body’s ability to reproduce to the first time, and having to consider fertility in the context of these new physical characteristics may feel premature. After the initial cancer diagnosis, changed appearance and feeling sick are common physical issues expressed by AYAs. Hair loss or baldness is most worrisome when asked about appearance (Neiman et al., 2007). Nausea, vomiting, and fatigue are the most common physical ailments experienced by individuals receiving cancer treatment. These physical issues are self-limiting but potentially detrimental to AYAs searching for their identity and forging new relationships. During and after cancer treatment, women may experience symptoms of early menopause, osteoporosis, and delayed pubertal growth (Crawshaw & Sloper, 2010). The various physical changes and potential fertility impairment that come with cancer treatment can be viewed as taking away many female characteristics that are important in the transition from young adolescence to womanhood, such as hair loss and the ability to carry and have a child.
**Cognitive Psychological Issues**

AYAs experience cognitive changes during this transitional phase from childhood to adulthood. The AYA brain transitions as the pre-frontal cortex begins to mature, allowing for more logical decision making and less impulsive behaviors (Feldman, 2008). The incomplete cognitive and emotional development of AYAs renders them not fully prepared to manage as complex a decision as whether to undergo FP. Recent qualitative research identified that AYA have difficulty making the FP decision. Hokkanen et al. (2004) conducted focus groups with 60 girls ages 13-18 that showed the adolescents did not consciously plan for the future and may not be cognitively prepared to make an FP decision. Younger AYAs may have a “here and now” frame of mind that is typical of their age group and may not be prepared to fully weigh the long-term implications of their decisions. However, Burns et al. (2006) suggest younger AYAs (females age 10-21) think about the future and are able to think about their life after cancer treatment, supporting that AYAs are cognitively prepared to make an FP decision. Even if AYAs think about the future and their life after cancer treatment, the FP decision can potentially be more difficult because some AYAs may not have decided whether they want children, may not be in a relationship or may not be in a relationship that warrants a discussion about having children. This decision may create dissatisfaction years later when motherhood becomes more important for these survivors.

**Interpersonal Issues**

The quest for autonomy and independence from parents increases during the teen years and into the early 20s. Self-concept and self-esteem begin to shape the identity of adolescents and continue to develop into early adulthood. Peer relationships are
extremely important to adolescents and time spent with peers increases as adolescents yearn to belong to and identify with their peer group. Young adults in their 20s and 30s are planning for the future, entering more intimate relationships, and gaining a sense of belonging with their peer group. A cancer diagnosis abruptly derails these important developmental processes, thrusting the individual back into uncertainty and sometimes a dependent state (AYAO PRG, 2006).

Studies on the experience of growing up with cancer suggest AYA go through a nonlinear or cyclical interpersonal transition from adolescence to young adulthood (Lewis et al., 2013; Crawshaw & Sloper, 2010; Horowitz & Bromnick, 2007). AYAs with cancer reported “moving back and forth” between independence and dependence on parents, social integration and isolation with peers, and reintegration to the academic and career setting. Accelerated development occurred when the adolescent faced decisions related to their healthcare and discussions with parents that felt more like adult discussions than a discussion between parents and their child (Lewis et al., 2013). Arrested development occurred when the AYA experienced physical side effects of cancer treatment that limited their ability to attend school or work and interact with peers (Lewis et al., 2013).

For AYAs with cancer, relationships, independence, and social worlds are in a state of suspension. The process of gaining autonomy from parents is challenged as younger AYAs require more care from parents during cancer treatment and after. Likewise, older AYAs may lose independence and require more care from family and friends during and after treatment. Peer relationships and social interactions are complicated by the physical effects of treatment. Fatigue is commonly reported as
inhibiting daily activities and activities with friends and family. Social interaction in the academic and employment setting suffers during and after treatment because of medical appointments and physical side effects of treatment. After treatment, AYAs report they are “different” from their peers and feel they have less in common with peers or fear rejection, stigmatization, or bullying (Lewis et al., 2013).

**FP Decision-Making**

Much of the research on FP decision making among survivors of cancer focuses on communication between the patient and provider, barriers to communication about FP from the provider perspective, and patient attitudes toward FP. Making a decision about FP requires information about the available options and time to think and discuss the options. However, FP information and referrals to FP specialists are still not standard practice and the FP decision must be made quickly, before the start of cancer treatment.

Young adult and adult women with cancer consistently state the difficulty involved in mentally processing a cancer diagnosis and the influx of information provided to them about cancer. Decisions related to their cancer diagnosis including FP need to be made very rapidly even though they may not have fully processed the information (Corney & Swinglehurst, 2013). Studies of AYAs between the ages of 24 and 44 identified the difficulty surrounding FP decision making not related to cognitive immaturity but because the women were under a great amount of stress and did not have time to fully process all the information (Corney & Swinglehurst, 2013; Kirkman et al., 2012).

AYAs are faced with a dilemma when making an FP decision. They need to decide whether they should delay treatment to pursue FP or forgo FP and start cancer
treatment right away. If treatment is delayed to pursue FP, that delay could adversely affect their health. On the other hand, not pursuing FP may negatively affect their fertility, as well as their emotional and psychological well-being. For many AYAs this may be a difficult decision to make quickly and may lead to decisional conflict (Mersereau et al., 2013). AYA FP decision making literature recognizes the difficulty surrounding the FP decision (Peddie et al., 2012; Quinn et al., 2011) but few studies explore the AYA cancer survivors’ satisfaction regarding the FP decision in the context of cancer.

**Psychosocial Effects of Infertility, Perceived Infertility and Uncertain Fertility on AYA Cancer Survivors**

Infertility has a negative impact on the wellbeing of female cancer survivors. Studies of adult female cancer survivors indicate that some women find the loss of fertility following cancer treatment almost as devastating as the initial cancer diagnosis (Schover, 2005), and studies with survivors of childhood cancer who experienced impaired fertility suggest a reduced quality of life and emotional distress (Crawshaw & Sloper, 2009; Nieman et al., 2007). Interviews with young cancer survivors reveal that becoming parents is a very important component of their perception of their quality of life (Schover, 2005; Zebrack et al., 2004). Female survivors of cancer report being motivated to become parents as a means to achieve a degree of normalcy in their lives. Some individuals report that having cancer increased their desire to have children, as the experience of cancer "increased the value they placed on parenthood and family ties" (Schover, 2005). Few individuals reported that their cancer decreased their desire to have
children, or that they felt their health status was a significant obstacle to becoming a parent (Schover, 2005).

Perceived infertility and the uncertainty about fertility can also have detrimental effects on cancer survivors. Janson et al. (2009) showed that even a perceived loss of fertility resulted in the reduced likelihood of being married and a higher likelihood of divorce. Zebrack and colleagues (2005) interviewed 32 male and female childhood cancer survivors between the ages of 19 and 37 about their fertility, desire to have children, and sexual practices. Of the 32 survivors, 19 (59%) were uncertain of their fertility status. This uncertainty led some female survivors to avoid or delay discussing their fertility status with their partner because they had experienced rejection or feared being rejected by their partner. A similar study of Australian men and women between the ages of 16 and 29 at the time of interview who were diagnosed with cancer between the ages of 10 and 22 asked participants about the effects of cancer on their social lives (Lewis et al., 2013). Men and women that started intimate relationships after their cancer treatment ended expressed that they had major preoccupations with discussing their uncertain fertility status with their partner. Halliday, Boughton, and Kerridge (2013) interviewed 12 women that were at least one year post-diagnosis for hematological cancer and between the ages of 25 and 39 years about their fertility status and the impact of their fertility status on their lives. All 12 participants classified themselves as different regarding their fertility status in comparison to their peers, based on their own expectations and societal expectations of women. The young women reported a “sense of detachment and difference or alienation, isolation, and sometimes marginalization” (p. 251) in regard to their fertility.
Conceptual Foundation for the Dissertation

Increased cancer survival rates and the advancement of curative treatments set the stage for AYA cancer survivors to confront long-term health issues such as uncertain fertility or infertility. Recognition of the effects of cancer treatment on fertility has led to healthcare providers playing a role in educating cancer patients about treatment effects on fertility, what options patients have to preserve fertility, and the FP decision. Health providers also have a role to play in assisting cancer survivors with their long-term adjustment to the fertility-related effects of their treatment. Ongoing work is needed to clarify the FP and fertility-related experiences of AYA cancer patients/survivors as a means of improving clinical and adjunctive care at the time of FP decision-making and over the course of survivorship. FP and the resulting effects are a long-term process just like cancer. Healthcare providers, and specifically nurses, play important roles throughout the process to educate, guide and assist cancer patients/survivors. In keeping with this longitudinal conceptualization of the FP process, the conceptual underpinnings of this dissertation were drawn from the Model of Care across the Cancer Continuum (Hudson, 2005).

Model for Care across the Cancer Continuum

The Model for Care across the Cancer Continuum (Hudson, 2005) encompasses longitudinal care from cancer diagnosis until death. The continuum of cancer care includes risk assessment, primary prevention, screening, detection, diagnosis, treatment, survivorship, and end-of-life care (Figure 1). Movement across the span of the cancer care continuum involves several types of needed care, as well as transitions between the types of care. Types of care refer to the care delivered to accomplish a specific goal, such
as detection, diagnosis, or treatment. Cancer diagnosis, long-term survival, and survivor and health resilience are the three types of care within the model. Transition refers to completing one type of care and moving into another type of care, such as from diagnosis to long-term survival after successful completion of treatment. Each type and transition in care is subject to influences at multiple levels that can facilitate or impede successful achievement. Primary intervention measures, starting from cancer diagnosis, and secondary intervention measures, when long-term survival is achieved, are necessary to transition to the next type of care and reduce cancer-related morbidity (Hudson, 2005).

Cancer care requires longitudinal follow-up after the initial diagnosis. For AYAs diagnosed with cancer, the transition from diagnosis to survivorship also may require an additional transition from pediatric care to adult care.

FP is relevant in the cancer continuum at multiple time points: cancer diagnosis (when FP needs to be introduced and decisions made), long-term survival (when fertility assessment and the fertility-related consequences of cancer treatment are experienced), and survivor health and resilience (the psychosocial aftermath of FP decisions and
outcomes). FP during cancer diagnosis includes discussing cancer treatment effects on fertility, determining what FP options are available, and making a decision about FP. The FP decision made during cancer diagnosis impacts the long-term survival stage and survivor health and resilience stage. The impact the FP decision has on both stages depends on the cancer survivor’s future plans regarding procreating.

To date the Model for Care across the Cancer Continuum model has not been used in the context of FP. It has been applied in studies of AYA survivors of cancer that are focused on the transition from pediatric to adult care (Nathan, Hayes-Lattin, Sisler & Hudson, 2011), psychosocial challenges (D’Agostino & Edelstein, 2013) and education and health promotion (Hudson & Patte, 2005). Nathan et al. (2011) suggests the Model for Care across the Cancer Continuum is useful in facilitating the transition from pediatric to adult primary care, especially after cancer treatment. The model allows the adult primary care physician to recognize specific health risks unique to cancer survivors and integrate risk prevention into the patient’s plan of care. In a study of adult survivors of cancer aged 18-35, D’Agostino and Edelstein (2013) used the model to inform future age-appropriate program development based on the psychosocial challenges identified by young adult survivors. Hudson and Patte (2005) encouraged healthcare practitioners caring for cancer patients to educate patients about cancer-related health risks and risky health behaviors by using the Model for Care across the Cancer Continuum.

This study applied the Model for Care across the Cancer Continuum by exploring AYA cancer survivors’ views on the treatment issues of FP at multiple time points across the cancer continuum. The transition issues at two stages of the cancer continuum were
also explored, asking participants to recall their experiences during the period when FP decision making took place, as well as their long-term adjustment related to fertility.

Summary

FP is an important piece of the AYA cancer care continuum and has implications at various points across the care continuum for AYAs and their healthcare providers. Due to the psychological and psychosocial effects the FP decision has on AYA cancer survivors, exploring the experiences of AYA cancer survivors regarding fertility and FP may lead to improvement in care across the cancer continuum. This dissertation applied the Model for Care across the Cancer Continuum to gain an understanding of the views female AYA cancer survivors have toward their fertility, FP decisions and the impact it had on their lives, their satisfaction with the FP process, and recommendations for clinical improvement.
CHAPTER 3: Methodology

The purpose of this dissertation was to explore the experiences of female AYA cancer survivors regarding their fertility and the FP decision. This study aimed to gain an understanding of the views female AYA cancer survivors have toward their fertility, FP decisions and the impact those decisions have had on their lives and their satisfaction with the FP decision. The findings will inform researchers and clinicians as they work to improve care across the cancer continuum, specifically FP discussions at cancer diagnosis, FP decisions before and after cancer treatment, and managing fertility-related issues after cancer treatment.

Qualitative Study Design

A qualitative descriptive design was used to guide the conduct of this study. Sandelowski (2000) describes qualitative descriptive design useful to obtain “straight and largely unadorned answers to questions of importance to practitioners (p.337).” It is intended to convey the subjective experience of the participants without interpretation by the researcher, until the data analysis phase. There is no pre-selection of variables to study and no commitment to a theoretical view of a phenomenon (Sandelowski, 2000). This approach is useful to gain a broad description and understanding of a phenomenon. Because few studies focus on female AYA cancer survivors’ FP decisions, the impact of the FP decision on their lives and their satisfaction with the FP decisions, qualitative descriptive design will allow the researcher to gain a general understanding of the female AYA cancer survivors’ subjective experience regarding the FP decision, its impact and satisfaction with the FP decision.
Participants and Recruitment

AYA cancer survivors were of particular interest because it is an understudied population and few studies address the AYA experience with their fertility after cancer. The National Cancer Institute classifies AYAs as individuals that are diagnosed with cancer between the ages of 15 and 39 (Adolescent and Young Adult Progress Review Group, 2006). In keeping with the NCI classification for AYAs, this study included individuals diagnosed with cancer between the ages of 15 and 39.

Participants were recruited through cancer survivor support groups and social media so as to enroll young women treated at a variety of hospitals throughout the United States. Locally, in Miami-Dade County, brief presentations explaining the study were made at cancer survivor support groups; flyers with study information and the principal investigators contact information were posted at local cancer centers that treat the AYA population and cancer survivor support group locations. Social media recruitment was done through Facebook and online discussion boards for cancer survivors. A study page with a brief description of the study and the principal investigator’s contact information was created on Facebook. The study page was shared with Facebook cancer survivor groups for recruitment on a national level. Additionally, study flyers were posted on online cancer survivor discussion boards and e-mails blasts with study information were sent to AYA cancer survivor listservs. If interested, women contacted the principal investigator via phone or email and were screened to identify eligibility (see Appendix A). In order to be eligible to participate the women had to be between the age of 18 and 39 years old at the time of interview, a cancer diagnosis was received during or after 2007 (ASCO guidelines were published in June 2006 and adopted more widely by
clinicians in 2007) because these survivors are more likely to have had a discussion about FP with their healthcare providers, age 15-39 when a diagnosis of cancer was received, and off cancer treatment for at least 6 months. If eligible, the study was further explained and any questions were answered. For the women that agreed to participate, a demographic survey (see Appendix B) and an individual in-depth semi-structured interview (see Appendix C) were conducted in person or via telecommunication such as Skype or Facetime. Interviews were conducted until saturation was reached. Each interview lasted approximately 45 to 90 minutes, mean time of 66 minutes, and was audio recorded for data analysis. All interviews took place in a private location that the women felt comfortable discussing their experiences. All information collected was kept confidential. Women received a $20 gift card after completing the interview as compensation for their time.

**Data Collection**

The in-depth interviews were semi-structured and the guide was developed from the stages of the Model of Care Across the Cancer Continuum: cancer diagnosis, long-term survival, and survivor health and resilience along with the three aims of the study. The interview script was designed with probes to ensure key topics were discussed with each woman. Key topics focused on the FP decision, beliefs about fertility, impact of fertility, and advice and improvements to the fertility and FP discussion. All interviews were conducted by the principal investigator.

**Data Analysis**

Thematic analysis was used to analyze the data. This analysis strategy allows for both manifest and latent content to be integrated in data analysis and themes need not be
based on frequency but instead captures something important in relation to the overall research (Vaismoradi, Turunen & Bondas, 2013). Manifest content refers to the surface meaning on the data while latent content refers to the underlying ideas of the data. Data collection and analysis occurred simultaneously. Audio files were transcribed verbatim using Microsoft Word. Transcripts were read multiple times to gain familiarity with the data. Initial codes were generated using NVivo 11. Codes were assembled into categories. These categories were grouped into potential themes and themes were reviewed to determine if they “work in relation to the coded extracts and the entire data set” (p. 87) as described by Braun and Clarke (2006). In searching for themes, eight potential themes emerged. After ongoing analysis, the data were refined to four themes: unpredictability of life, loss: the toughest pill to swallow, relationships: struggling to meet societal and familial expectations, and moving on with life. These four themes encompass the experience of the female AYA cancer survivors regarding their fertility and FP decision.

**Study Trustworthiness and Validity**

The trustworthiness of the study was upheld in several ways. To ensure confirmability and dependability of the study, an audit trail of data collection and analysis procedures was kept (Marshall & Rossman, 2011). A dissertation committee member with expertise in qualitative research independently coded 20% of the data to ensure dependability and met with the principal investigator to review findings, assess inter-rater reliability and discuss any divergent findings (Lincoln & Guba, 1985). The validity of the study was maintained by developing an interview guide consistent with the research questions and reviewing or modifying interview questions as needed. Rich descriptions of
the findings were included for readers to learn about the experiences of female adolescent cancer survivors regarding fertility and the FP decision based on their own words. The rich descriptions of the findings also allow the reader to connect the participants’ experiences to the themes and the Model for Care Across the Cancer Continuum.

**Protection of Human Subjects and Data Safety**

Protection of human subjects is of utmost importance and multiple safeguards were in place to ensure participant protection. No human subjects activities took place until study approval was received from the University of Miami Social and Behavioral Science Institutional Review Board. In order to protect all participants’ confidentiality, interview transcripts were de-identified and any identifying information was stored in a locked cabinet only accessible to study personnel. Digital audio recordings were transferred from the device to a password-protected file on a password-protected computer. Only study members and those authorized to review data for quality assurance or audit purposes had access to data. All study personnel were certified to conduct human subjects research through the Collaborative Institutional Training Initiative (CITI).

A waiver of documentation of consent was received so that interviews could be conducted via telecommunication technology (e.g., Skype, Facetime). Prior to verbal consent, the principal investigator explained the study in detail, answered any questions, and obtained consent to record the interview. The consent form clearly stated that participation was voluntary and the decision to participate, not participate, or discontinue participation would not affect any services they received from their healthcare provider or
at their cancer center. The principal investigator reiterated that it is the participant’s right to withdraw from the study at any time and their participation would not affect any services they receive from their healthcare provider or at their cancer center. Each participant was offered a copy of the consent form. A consent progress note was written for each participant, noting the participant agreed to participate in the study, if any questions were asked, and that a copy of the consent form was sent to them if desired.

Due to the nature of the study, the principal investigator encouraged participants to alert her if they experienced anxiety, emotional distress, fatigue, or other negative reactions while participating in the interview and they could stop the interview, take a break or withdraw from the study. A list of referral services was available for women if they experienced any negative reactions; as no women reported any negative reactions during the interview referrals were not necessary. Although the interviews were very emotional at times, none of the women felt it necessary to stop or terminate the interview. All interviews took place in a private, comfortable location of the participants choosing.

**Summary**

A qualitative descriptive design was used to gain an understanding of the experiences of female AYA cancer survivors regarding their fertility and the FP decision. Interviews with women were audio recorded and transcribed for data analysis. Numerous steps were taken to ensure validity and rigor during the data analysis process. Furthermore, steps were taken to ensure protection of human subjects and data.
Chapter 4

Results

Participant Characteristics

Data saturation was reached at the eighteenth interview. Participant ages ranged from 21 and 39, with a mean age of 33. Eleven (61%) participants identified as Caucasian, five as Hispanic (27%), one as African-American (6%), and one as Indian (6%). Five women underwent FP (27%); three underwent egg preservation (17%) and two underwent embryo cryopreservation (11%). The women underwent cancer treatment at various hospitals across eight states including Connecticut, Florida, Illinois, Massachusetts, Michigan, Ohio, Pennsylvania, and Virginia. At the time the interviews took place, seven women were single (39%), seven women were partnered (39%) and four women (22%) were divorced. Demographic characteristics of the study sample are presented in Table 1

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</tr>
<tr>
<td>3 children</td>
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<th>Children after cancer diagnosis</th>
<th>Count</th>
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<tr>
<td>2 children</td>
<td>2</td>
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<tr>
<td>Aborted pregnancy</td>
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<td>Adopted child</td>
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Overview of Themes

The interviews with young women survivors of AYA cancer revealed that experiences with fertility and fertility preservation are complex and change throughout the cancer continuum. Of the eighteen young women interviewed, four (22%) did not recall having a discussion regarding potential fertility impairment due to cancer treatment with their healthcare providers, four (22%) recalled having a discussion regarding potential fertility impairment due to cancer treatment but were not given any FP options by their healthcare providers and about half (56%) had FP options presented by their healthcare providers during their discussion regarding potential fertility impairment.

These young women described the real life context of having to concern themselves with their fertility during cancer diagnosis, treatment, and survivorship. Fertility and FP were intertwined with other aspects of the cancer experience and represented a small piece of the whole cancer and survivorship experience for participants. Although the fertility and FP experience is a small facet within the cancer continuum, fertility and FP can be challenging throughout the entire experience. The themes are not limited to fertility-related issues because the cancer-related issues discussed by the young women were clearly impactful and inseparable from the fertility and FP experience and thus are presented within each theme.

Four themes emerged from young women cancer survivors’ experiences with cancer, fertility and FP: 1) Unpredictability of Life, 2) Loss: The Toughest Pill to Swallow, 3) Relationships: Struggling to Meet Societal and Familial Expectations, and 4) Moving on with Life. The final thematic map (Figure 2) illustrates the themes, categories and, in some cases, subcategories. The results for each theme follow the figure.
Unpredictability of Life

Uncertainty across the cancer continuum

Powerless but searching for control

Loss: The toughest pill to swallow

Damaged goods: loss of the female identity

Grieving: an actual or potential loss

Relationships: Struggling to meet societal and familial expectations

Family Ideals and Priorities

Support makes the impossible possible

Family

Friends

Faith

Moving on with Life

Dating and Relationships

Reintegration to work/school

Outlook on Life

Figure 2: Final thematic map, showing final four main themes
Theme 1: Unpredictability of Life

Fertility after cancer treatment was unpredictable for many of the young women survivors. The unpredictability was characterized by a sense of uncertainty and feeling powerless. Unpredictability transcended other aspects of the cancer experience for these young women such as survivability and relapse. These women commonly discussed how their bodies and lives changed after they were diagnosed with cancer. These changes led to the women feeling powerless and searching for ways to regain that power. This theme was comprised of two categories: 1) Uncertainty across the cancer continuum and 2) Powerless but searching for control.

Uncertainty across the cancer continuum. A common challenge revealed by many of the young women was uncertainty. All women experienced uncertainty at one or multiple points throughout the cancer continuum. Many women recalled feelings of uncertainty regarding survival and the potential for relapse at the time of cancer diagnosis and during treatment. More than half of the women had feelings of uncertainty regarding their fertility. Uncertainty with fertility was complex in that some women were unsure if they could get pregnant naturally or through other methods such as in vitro fertilization. Others were unsure if they could physically carry a child. One young woman experienced a few unexpected complications after she was diagnosed with cancer. She said:

I – my chemo took a lot of unexpected turns like extra radiation, relapse in bone marrow and everything which wasn’t part of the original plan; and given that I didn’t know – nobody really knew for certain how it was going to go for me.
All young women that wanted to have children in the future expressed their concern with their own health and survivability when considering having children. Uncertainty experienced by the young women survivors with their own future health led to concerns with their ability to get pregnant, carry a child and have a healthy child. As one woman expressed:

I don’t know that it’s the smartest thing to have children when I still feel that potentially there’s a higher likelihood that I could leave them. I look at it like if there’s any possibility that my genetics pass to them that’s not fair. I have no interest in doing that so I sort of think that’s how I see my fertility now not knowing I don’t know if I can have children. I mean I physically did not have those organs removed but I don’t know if I produce enough estrogen and such to get pregnant.

Women who preserved eggs or embryos experienced feelings of uncertainty with accessing and using the preserved eggs or embryos in addition to concerns with their ability to carry and deliver a healthy child and their own health. Specifically, they expressed concern with the viability of the eggs or embryos, whether they would be able to use the eggs or embryos, if in vitro fertilization would be successful, and if they would have multiples due to the in vitro fertilization. When asked about fertility one woman said:

Just having to go through the hormone shots again and having to do the implanting. Concerns about carrying the child in my uterus. There’s concerns will my hormones actually be sufficient to carry a child full term. Concerns about my hip, my hip was actually where my cancer was
located. Will my hip be able to carry a baby? I definitely tell people one of my biggest fears is having multiple children at one time like twins. I didn't even know once I had my eggs frozen if I'd want to go back and go through all of the in vitro and all of that like that's a big ordeal.

Uncertainty was a difficult aspect of the fertility experience all young women experienced. Many women experienced uncertainty throughout the cancer continuum and discussed their struggle in dealing with uncertainty. Others only felt uncertainty at specific times. Although their experiences with fertility was the focus of the interviews, many of the young women discussed their feelings of uncertainty with other aspects of their cancer such as survival and relapse.

**Powerless but searching for control.** Lack of control was seen as a struggle for many of the women as a result of their cancer diagnosis. Some women felt a lack of control because their healthcare providers made most of the decisions related to cancer treatment. The unpleasant side effects that accompanied treatment such as hair loss and potential fertility impairment left some women feeling like they had little control over their bodies. Many of the young adults that were independent before their cancer diagnosis had to become accustomed to being dependent and relied on family and friends to help with typical activities of daily living. The changes that these women experienced with their cancer diagnosis left them searching for control.

Educating themselves regarding their cancer diagnosis and the affects their treatment may have on their bodies was one way for some women to gain control. After one young woman was diagnosed with cancer, her sister sent her a book so she could educate herself about cancer and what to expect. Reading the book her sister gave her
helped provide her a sense of control and better understand how her fertility may be affected and for that she was very grateful.

I was very thankful that I have the book that gave me direction and it also actually gave me a sense of control to have all of these things to pursue and look into and you know something I could do to determine my path a little bit. So it was actually at the time, you know, it was a little - I was very upset about the idea of losing my fertility but I also decided to take the information I had and just sort of run with it. That gave me a sense of purpose and control.

Other women were able to gain control by shaving their heads before their hair started falling out. Shaving their heads prevented cancer and treatment from taking a piece of them. It was their decision and their choice.

My hair, my hair had always been thick and long and beautiful so when the hair started to fall really bad I actually made a decision that I was gonna shave it all...when you have cancer and you can’t control it, you feel powerless because you wanna get better and you do everything you can but sometimes things just don’t go well and it doesn’t work, but one of the things about shaving your head before it all goes, before the whole thing falls off or the chemo kills it is that it gives you a sense of control, like I control something. So I just shaved it all off.

Some women were never able to find the sense of control they were looking. A young woman who was weighing the pros and cons of fertility preservation yearned to connect with another young woman cancer survivor that
went through the process of making a FP decision. She hoped that hearing another survivor’s experience would provide some insight in making her own FP decision. She searched for a young woman cancer survivor who could share her experience with fertility and fertility preservation but was unsuccessful.

I was desperately searching for ways to find somebody who had gone through something similar but at my age um to bring me the insight that I was looking for…when I had to make those decisions before I had surgery... It was what I was searching for and not finding which was some organization or agency to find somebody on the other side of it roughly near my age who had faced the same thing with potentially changes your body changes your fertility to share their experience to tell me it was going to be ok.

**Theme 2: Loss: The Toughest Pill to Swallow**

For many young women interviewed, fertility served as a defining factor of their female identity. Diagnosed or perceived infertility became a source of loss and impacted their identity. Additionally, some women experienced miscarriages and changes in sexual health that became a source of loss. With these losses came grieving. Whether the loss was an actual loss such as a miscarriage or diagnosed infertility, or a potential loss such as perceived infertility, a period of grieving followed. The loss and feelings of grief were, in most cases, more challenging than cancer treatment because unlike cancer treatment, there is no timetable when it comes to dealing with loss and grief. This theme was comprised of two categories: 1) Damaged goods: loss of the female identity and 2) Grieving: an actual or potential loss.
**Damaged goods: loss of the female identity.** Infertility, perceived infertility and uncertain fertility status was a concern for almost all the young women interviewed that challenged their identity. For example, a woman describing her conversation with her partner when she was 27 regarding having more children said, “I cannot, it will never happen, I cannot give you any more children. And I don’t know if it was me being a woman, or you know, maybe we should get divorced, I can’t.” Another woman described her feelings about her possible infertility as feeling “less of a woman” Other women also discussed this phenomenon, regardless of whether they already had children or were reflecting on their ability to have their first child.

Most of the women regardless of whether they were in a relationship or single discussed their fears of losing their current partner or future partner because they were “broken” and may not be able to “produce any more children.” When describing how fertility has affected her life an ovarian cancer survivor said, “If my sisters ever need me, because we’ve always all talked ‘I’ll be a surrogate [mother] for you if you if I ever need it…’ you know, I couldn’t do that, I was damaged goods.” It became evident fertility was an important piece of their female identity, and losing fertility or uncertain fertility, represented a loss of part of their female identity.

Changes in their sexual health during and after cancer treatment was another source of loss for many of the young women. Some were pre-menopausal or in a state of early menopause because of their cancer treatment or due to medication they were taking after treatment to decrease their chances of relapse. They experienced loss of libido,
mood swings, vaginal dryness, and vaginal stenosis. One woman described her sexual health and lack of sex drive after treatment by saying:

My vagina is really tight. I hate it. It hurts. It's gross. I hate it. If - if he was to come, it's to the point where he comes over here sometimes - we come to my home. We just sit down and watch tv. I never initiate sex ever. If you go to wait for me to start off, you got to lift your own weight because I'm never starting it off. I don't even think about sex. Period. No way it's done.

Another young woman experienced similar pre-menopausal symptoms and her concern with having to be in a pre-menopausal state until she is ready to naturally go into menopause.

Like I have to take hormones until I the day, I actually go into menopause, I’m at that age. With the hormones I have to worry about breast cancer and, you know all this other side effects for it. And then it’s affected my life in the sense that my sex drive isn’t the way it should be for a 33, 32-year-old.

For women that are single, becoming intimate with a new partner can be difficult to negotiate due to the sexual changes after cancer treatment. One woman said:

How are you supposed to say well before we have sex there is something we have to discuss I don’t have natural lubrication so I mean how do you go about talking about that kind of stuff?

Although interviews were focused on fertility, hair loss from cancer treatment was discussed at various points throughout almost all the interviews. Hair loss can be viewed
as part of a woman’s identity and hair loss from cancer treatment tormented many of the young women interviewed. When talking about her cancer experience she said, “it was really hard to not fall into the place of oh I look so bad, I don’t have my hair, and I don’t have my color, and everything hurts.” This loss was different from the other losses experienced by these young women because it was a short-term loss and in time, their hair grew back, “To me hair was hair. Hair grows back”. On the other hand, one woman felt very strongly about doing everything she could to prevent losing her hair during treatment because she worked throughout her treatment. She explained, “I didn't lose my hair because I wore these penguin cold caps that freeze your hair so I didn't - since my hair didn't fall out, I would say that if it were to fall out that would've been the worse part of the chemo.”

**Grieving: a potential loss or actual loss.** Many of the young women interviewed experienced grief over loss of fertility at some point after their cancer diagnosis. This grieving process was delayed and was not experienced until after treatment was completed. The overwhelming nature of the initial cancer diagnosis and start of treatment placed their focus on surviving cancer. After treatment as women began to feel better and suffer less from side effects, the grieving process emerged. The grieving process had no time line and was unique to each young woman. These women grieved or were still grieving the loss of fertility at the time of the interview. However, most were not diagnosed with infertility and were grieving the perceived loss of fertility. These discussions were very emotional with periods of crying.

Some women experienced an actual loss such as being diagnosed with infertility or suffering a miscarriage. For example, after being told by her
physicians she was infertile and thinking about how the infertility would affect her future one participant said, “I mean it's really emotional to want something to happen and you know that you can't. And the reason that you can't is because your body won't. Your body won't do it for you.”

A young woman that underwent egg preservation and stored her eggs for a few years discussed the difficulty in deciding how long to keep those eggs and if having children was a reality for her:

For a while I kept thinking well I can still hold onto my eggs because it's again just $400 a year that's a small price to pay for the possibility of having kids. But as it - as I got further and further away from that and more certain that I wasn't going to have kids…I eventually was like I have to just let them go so that I can move on and sort of…I don't want to have them sitting out there knowing I'm never going to use them…

Ultimately she decided to destroy the eggs because she felt it would provide her some closure. When she received a letter in the mail from the hospital where the eggs were being stored stating the eggs were destroyed she described her feelings as:

I think the finality of it does help just to bring some sort of relief or I'm not really sure what emotion it is I'm experiencing because I let those eggs go but I guess just holding on to some sort of false hope wasn't - didn't feel healthy to me.

Shortly after completing treatment for breast cancer a 39-year-old woman was told by her oncologist she couldn’t have children. Due to her age she felt time was of the
essence and her and her husband decided to try adopting. At the time, she was only out of treatment six months and their application was denied. The rejection from the adoption agency on top of being told she could not have children caused profound feelings of grief.

I’m a little bit older and we always said yes, that’s a possibility and actually when my doctor told me no kids I impulsively filled out an application for adoption online with one of the most well-known agencies in the country and was rejected because of the cancer and that was actually really devastating.

One participant, a two-time cancer survivor, preserved eggs before undergoing treatment for her second cancer diagnosis. After treatment she and her husband decided to start the in vitro process (IVF) to get pregnant. She highlighted how intense the IVF process can be for women and their families. The IVF process can be another source of loss for the young women. It is not uncommon for frozen eggs to no longer be viable, the embryo does not implant in the woman’s uterus, or have a chemical pregnancy during the IVF process. This can be especially difficult because these women have a limited number of eggs or embryos frozen. A woman that went through the IVF process stated:

They called and they said that I was pregnant and so we were super excited and I thought oh what about all those other people who have gone through this, you know, maybe I’m gonna be the lucky one and it’s gonna work for me. And so we have to go back for regular testing during this time. So that Thursday I had gone for a pregnancy test, they told me I was pregnant and then 2 days later you go back for another pregnancy test and at that point they told me it was a chemical pregnancy it wasn’t a viable
pregnancy. So those 2 embryos were then gone and we had 5 on ice, so we had 3 left.

After the chemical pregnancy, her fertility doctor suggested trying to retrieve more eggs before trying to transfer additional embryos in case those embryos did not implant. Her doctor was able to retrieve 8 additional eggs. This was the process she went through after the retrieval:

They will say: ok you have 8 eggs that are good or viable or whatever, and then they will do a transfer, it wouldn’t work and then they might be able to freeze 1 or 2 of them. And then we will do a transfer with that and it wouldn’t work and then I would go through a whole new set of fresh IVF meds and go through the whole procedure all over again and none of them worked…I finally went ahead and had that egg transferred and I got pregnant and, um, it was a miscarriage. I was about 8 weeks pregnant and we went and saw the heartbeat and then I went for an ultrasound and they just said the baby was not on the right spot and the heartbeat was falling down…I was just gonna let nature do what it needed to do and hope maybe they were wrong and then that weekend, that Sunday, I lost the baby. That was the end of my eggs.

Some women grieved a potential loss. A 30-year-old recently married breast cancer survivor started thinking about having a family and at that point the potential that she may never have biological children became real. Her oncologist strongly suggested she refrain from getting pregnant for at least 5 years because her breast cancer was hormone dependent. She described her feelings at that point and stated:
This was a huge blow for me as all I wanted to do was be a mom, have kids, get pregnant go through the experience. It took a long time to come to terms. It took me a full year to not cry, be upset for every friends that had a baby, got pregnant whether they kept it whether they had a miscarriage. Everything hurt um and I mean I cried for hours and hours and hours. Very hard. Now it hurts but I’m not crying. I’ve accepted it and I had to go through the stages of grieving because it is a loss. I didn’t realize it until I finally felt ok about it.

Some women eventually accepted that the life and family they imagined they would have one day was not a reality. That acceptance was achieved through the grieving process and took time. In some cases, women sought the help of a therapist to help them work through their grief. The grieving process proved very challenging for many women:

I cried a lot and I honored my feelings and I worked through it in therapy and you know, my husband supported me and I mean, I could cry about it now. I had to basically grieve for the life that I thought I might have or that I wanted you know. It took a long - it took a long time and I would make progress and then have set backs and there are times when it just gets to me a little bit but for the most part I do feel like I'm through the majority of that and I've accepted that this is my life and that's okay you know. I can be okay without having kids without having a family so its yeah definitely a grieving process.

Loss, actual or potential, was experienced by all women regardless of their age or marital status. Almost all women experienced loss in regard to their female identity through hair loss or fertility. Experiences with miscarriages, adoption
denial, and perceived infertility led to women to grieve their losses. Through the interviews it was evident their experiences with loss and grief were more difficult than the actual cancer diagnosis and treatment.

**Theme 3: Relationships: Struggling to Meet Societal and Familial Expectations**

Fertility proved to have an impact on relationships with partners, family, and friends. Fertility issues or perceived fertility issues added another dimension of complexity to relationships. Many of the women felt pressure to live up to society’s expectations of women and their upbringing played a role in shaping these young women’s ideas of what their ideal lives should be. In some cases, this pressure was relieved and a new ideal life was accepted with support from family, friends, and faith. Therefore, this theme was comprised of two categories: 1) Family Ideals and Priorities and 2) Support: makes the impossible possible.

**Family ideals and priorities.** Young women who were given the option to preserve their fertility used their priorities to guide their decision about whether they should preserve their fertility. Most of the women that decided to forego FP made their decision because it was more important to “do what we have to do, get it [cancer] fixed and get it [treatment] over with” and even if they might not be fertile, they were alive. Their main priority was to overcome cancer and deal with fertility later. This idea resonated with many women. A 28-year-old lymphoma survivor, was surrounded by children her entire life since her mother owned and operated day care out of their home and “raising kids has pretty much been my life and I've always wanted kids and it's not - it's not hard to picture me raising kids” was “upset” when she found out she may not be
able to have children due to her treatment but decided to start treatment as soon as possible:

It was hard for me to picture risking my life by putting treatment off or having a surgery to - that I know is not like aggressive but still just another thing that could affect the outcome of my life. I was more concerned about my life than the life of potential, imaginary children.

On the contrary, a few women felt that having children was extremely important and they would do everything to preserve their fertility. These women all felt “I knew that I was gonna overcome that [cancer]” and were already thinking about the future. When their oncologist told them their treatment could affect their fertility they were in “shock” and would do anything to be able to preserve their fertility and cover the cost of FP.

I want to have a family. I do want to be able to have at least 1 or 2 kids and I was kinda like ya know I got to do this. I got to do something about it. Maybe I can apply for a loan. I was thinking of many possibilities at the moment. There was no chance that I was maybe yes maybe no ya know. That was a decision I made right away. We got to do this. We got to do our research. We got to do our research and look around and see what’s going on. So it wasn’t much ya know hard to make that decision cause I knew that somehow ya know that the possibility was there.

The priority for some women was having the option of having their own biological children in the future. A greater importance was placed on having options after cancer treatment if they were not able to get pregnant naturally.
My biggest concern at the time - and I just remember thinking you know I didn't want to have any regrets and that's - that's really what drove me to do it in the first place … But if I hadn't frozen my eggs and I wanted to do that later obviously I couldn't. So, when I made the decision I just thought you know I don't know what - I don't know what the future holds but I want to keep my options open and I don't want to regret not doing something and so I am - I am glad that I went forward with that and made that decision.

Some women expressed that having a family was a priority but because their cancer was hormone dependent their health could be in jeopardy if they underwent FP and got pregnant after treatment. At that point, having biological children versus non biological children was less of a priority to them. Many of the women that were very accepting of adopting had family members that were adopted or had interaction with adoptees.

My husband now looked at me and said, “Honey, we can adopt but I don’t want you to have any more estrogen I don’t need your cancer getting bigger.” I don’t need it spreading in the couple week time period because my particular cancer was quite aggressive. So having a supportive husband/ fiancée did help me make my decision. I’ve never been opposed to adoption as I have 2 family members that are adopted, my cousin and my brother and those are just in my family alone. So I knew I’d have a family I just didn’t know how.
Maybe adoption is a better choice for me than actually like having a full term pregnancy and like having my hormones all over the place when I'm already at an elevated risk for it because of the radiation. So, I don't really - I don't think there's anything wrong with adoption, I think it's beautiful. And, I think there's so many kids that don't have like families…it's just not going to be your biological kid. You can still be a parent.

Of the eighteen women interviewed, one had a child before she was diagnosed with cancer and one was pregnant when she received her cancer diagnosis. Those women were more concerned with being alive to take care of their existing or soon to be born child. Having more children was less of a priority and they were grateful to have their children and be alive to care for them:

I’m alive, and I could have died and left my daughter without a mother so now that I know that I can’t have any more children, and that I probably maybe, as a miracle, but probably never will. It doesn’t bother me! I mean, I wish I could, of course! You always wanna kind of have a bigger family but I rather be alive to take care of the one I have.

Concern regarding fertility has the potential to cause stress in intimate relationships. Young women that were single during treatment and after treatment expressed issues in finding a suitor that would accept a woman with possible fertility problems. For example, a single 30-year-old survivor was concerned about talking to future partners about her infertility and having to use IVF, “I can’t have kids and if we ever do want kids this is the amount of money you’re gonna have to pay if you wanna have a kid with me…” Similar concerns were echoed by other single survivors:
I’m 34 and most people I mean I guess I don’t know the average age of wanting children but most people want to get married and live the American dream have the kids and the house and all of that. For me to not being able to offer somebody that makes a big impact.

I mean, I thought I was a pretty good catch. You know, I was smart. I did all the stuff whatever. Now, it’s like this is a whole side of me that’s coming. It’s like a package deal…I feel like a big part of the goal of marriage is to have kids.

After some participants found out they may experience fertility impairment or infertility, they felt their fertility issues strained their relationship with friends and family members that got pregnant. Many of the young women never talked about these feelings with anyone other than a therapist because they “felt terrible” having those feelings toward a friend or family member. Acknowledging and accepting their feelings of envy toward other pregnant women was difficult. Many of the women never spoke of the envy they felt and instead, kept it to themselves. One woman acknowledged she had ill feelings for women who got pregnant and she felt it was “unfair” that she had to go through cancer and all the effects of cancer.

I definitely had a period of sadness, anger, jealousy, resentment - a lot of negative emotions that I didn't communicate with people but at least with the person who was pregnant.
Another young survivor that knew she was infertile discussed how hard it was to talk to her friends that had children when they complain about their children or when they discipline them for something trivial.

When you hear a parent say something bad about their kid and it’s just like I just wanna grab them by their shoulders and say open your eyes and imagine if you didn’t have [th]em. And they threaten to bust their butt or something I mean I know every parent is different but just hearing that sometimes it’s just hard.

Support makes the impossible possible. This category of support was comprised of 3 subcategories: 1) Family, 2) Friends and 3) Faith, which represented the sources of support that helped women transition from cancer diagnosis to survivorship. Support had the ability to “push you to keep going when you feel like giving up”. Many of the young women became very emotional when they talked about their support systems and how they were astounded by the outpouring of support they received.

Family. Parents and siblings were very important in helping these young women throughout their diagnosis and treatment. Of the eighteen women, only one felt she lacked support. Her experience was not as positive as the other women who had strong support systems. When she told her mother and sister they “thought she was playing around with them or something” and they did not believe she had cancer. She felt very alone throughout her cancer experience.

One woman lived in a rural area and had to travel three hours to receive treatment and almost two hours for FP. Without her family, none of that would have been possible, “my parents were the ones who were helping me through treatment and were my
caregivers throughout treatment.” Another young woman experienced “different emotions with the situation” but, “to be able to call up my sister and be like ‘I’m scared’ or you know, ‘I just need a hug’ or ‘I need you to tell me it’s gonna be ok,’” helped her express and accept the many emotions she was feeling throughout her cancer experience.

Many women credited their mothers support. Mothers were “there all the way” and the women’s “rock” through their entire cancer journey. An ovarian cancer survivor recalled only wanting her mother in the room after abdominal surgery and she wanted her mother to be the one to tell her if they needed to remove her ovaries.

I didn’t want anybody to tell me what had happened during surgery except for my mom. I ended up getting out of surgery very late. It was like 1 or 2 o’clock in the morning um I just requested that none of the doctors that no one talk to me. I wanted my mom to be the one to tell me.

**Friends.** Friends were important to keep social connections open during treatment, “you learn who your real friends are very quickly.” Women felt that their true friends made an effort to spend time at the hospital or the woman’s home and helped make the cancer journey a more positive experience. When asked about her support system a survivor in her 20s recalled:

You learn who is willing to sit on the couch and watch movies for six months cause you’re not supposed to be in public places but, my support system, it certainly would not have been the same positive experience without that.
Another survivor was grateful for her co-worker friends that wanted to help her get a wig when she lost her hair from chemotherapy. Her co-workers were able to get donations and buy her a wig.

I worked at a drug shop and the doctor told me that I was gonna lose all my hair and she took up a donation with customers and employees and had enough money to buy me a wig. That meant I guess it doesn’t have to do with fertility but that meant the world to me cause it’s something when your 20 years old you can’t just go out and buy one. It’s nice knowing so many people care about you going through something so horrible.

**Faith.** Faith was often discussed in the interviews as a source of support and gave many of these women strength to overcome cancer. One woman felt that cancer was more of a “crisis like a life altering event” for her support group friends who were not spiritual. Since she was Christian, she felt that her faith “really held me together and kept me stronger and reminded me that this is just a bump in the road and there’s always hope.” Some women found faith or became more spiritual during their cancer journey.

I was never very religious. I believe in God, but I’ve always felt like I don’t need to be in God’s house to pray or to talk to him and actually having this experience made me realize that even more; that he heard my prayers.

A few women who identified as Christian during the interview expressed their concern with the Catholic Church’s lack of support on FP. These women took this into consideration when they made their decision whether or not to move forward with FP but felt there should be an exception because they were fertile
until they received treatment for cancer. A few women went through with FP but one woman felt ostracized by her church and fellow parishioners after they found out she underwent FP and IVF.

Because we are Catholics and our religion is against IVF and so the church found out about it and they gave us an extremely hard time and they were completely unsupportive and they just made us feel awful on top of everything else that we were dealing with.

Theme 4: Moving on with Life.

Survivorship is often referred to as the “new normal” and comes with its own additional challenges. The young women that participated in this study identified two aspects of survivorship that were particularly challenging, relationships and work/school. Additionally, all participants made reference to how their cancer diagnosis changed their perspective on life and made them realize they were not invincible. This theme was comprised of 3 categories 1) Dating and Relationships, 2) Reintegration to work/school and 3) Outlook on life.

**Dating and relationships.** Women in a relationship at the time of cancer treatment who knew their fertility may be affected by cancer treatment, had multiple conversations with their partners about fertility and what their plans were for the future in regards to children. On the other hand, women who were single or divorced during treatment found it difficult to determine the best time to talk about their previous cancer diagnosis and fertility with new partners. Many women discussed their concerns with how and at what point in a relationship they should introduce topics such as “I’m a survivor of cancer” and “we may not be able to have biological kids” with new partners.
How and when to have conversations about their cancer and fertility with new friends and co-workers was also a concern. These women were concerned their friends and co-workers would treat them different after they learned of their cancer or fertility problems.

I think the integration into “normal” takes time and take like trial and error and ya know as far as getting back into dating is it a first date conversation is it a 5th date conversation because at some point you’re holding back information that is a big part of your life but it’s also like you don’t necessarily want to just throw that out there to anyone whether it’s like an employer or new love interest even a new friend like a girlfriend or a coworker like I’m very picky about who knows what.

**Re-integration to work/school.** Getting a new job or returning to the job you held before cancer proved difficult for a few young women. This difficulty stemmed from their appearance changes; the amount of time needed for doctor’s appointments; and the side effects from their cancer treatment. A woman who was just entering the workforce at the time of her cancer diagnosis said:

When you’re diagnosed with cancer at 23 and you have your whole career ahead of you it’s important for you this year of your life has a major impact on the rest of your life and how do you I mean when I interviewed for this job and for previous jobs post cancer I have more doctor’s appointments than the average 28-year-old or 32-year-old or 34-year-old like I don’t want you to think that I’m like going to other interviews cause I’m like going to a doctors’ appointment. Like I legitimately have more doctor’s
appointments than the average person and you need to be ok with that when hiring me um but that’s not an easy conversation.

**Outlook on life.** All the young women interviewed said they had a new outlook on life after cancer. They all learned to appreciate life more and not take anything for granted but, at the same time, were hyper aware of their own mortality. They used words and phrases like “grateful” and “I’m so thankful I’m alive” when describing their thoughts on life now that they are a cancer survivor. A young woman said:

It gives you a reality check that you’re not immortal. So when that hits you at age 22 you learn quick um that you’re not immortal and you really need to learn to appreciate every day as much as you can but um love. Love people. Love those around you. Treat other well and be kind because you never know what people are going through. But I think inner beauty was one of the biggest lessons through it all.

All the young women described survivorship as “tough” and the amount of time each woman was a survivor had no bearing on this description. Some were survivors for almost seven years while others were survivors a little over a year. Survivorship was not described as getting easier but “you just learn to deal with it better.”

**Summary**

The themes that emerged from the eighteen interviews describe the experience of young women cancer survivors. The cancer experience is multifaceted and encompasses many challenges. Fertility is just one of many challenges these young women face. Adjusting to life after cancer requires time and patience for each individual to determine
what works best for them. Coming to terms with fertility status is challenging but these women are grateful to be alive, and work to find ways to deal with their fertility status while maintaining their identity as a woman.
Chapter 5

Discussion

The purpose of this dissertation was to explore the experiences of female AYA cancer survivors regarding FP. This research contributes knowledge specific to the FP experience of AYA cancer survivors, the satisfaction of AYA’s with the FP decision, the impact of FP on their lives, and how their experiences can inform clinicians and future patients experiencing a FP decision. The purpose was accomplished through three aims: 1) Describe the views female AYA cancer survivors have toward their fertility and FP decisions; 2) Describe the impact fertility and FP decisions had on their lives and their satisfaction with the FP decision and process; and 3) Identify areas for improvement regarding FP across the cancer continuum as described by survivors of adolescent and young adult cancers. These findings inform researchers and clinicians as they work to improve care across the cancer continuum, specifically FP discussions at cancer diagnosis, FP decisions before and after cancer treatment, and managing fertility after cancer treatment.

The Model for Care Across the Cancer Continuum has not been applied previously in the context of FP. This model was used to guide this dissertation because it suggests there are three types of care an individual diagnosed with cancer transitions through, cancer diagnosis, long-term survival and survivor health and resilience. This model was chosen as the framework for this study because fertility and FP are relevant throughout the cancer trajectory and allowed the results of this study to inform clinical practice and policy at different stages of the cancer experience and ultimately, improve care across the cancer continuum for AYA cancer survivors. To improve care in the AYA
population, it is beneficial to understand where fertility and FP fit in each of the three types of care.

The purpose of this dissertation was accomplished through three aims. The following discussion will be organized by the aims. Each aim will have a discussion specific to the aim along with implications for practice. Four main themes emerged in the study: 1) unpredictability of life 2) loss: the toughest pill to swallow 3) relationships: struggling to meet societal and familial expectations and 4) moving on with life. These themes are described in relation to the Model for Care Across the Cancer Continuum in the following discussion. Although the focus of this dissertation was fertility and FP, other salient issues such as hair loss, sexual health, and transitioning from independence to dependence and re-integration to work or school were frequently discussed and will be presented under the respective theme. The repeated reference to these topics by the young women in this study showed just how impactful hair loss, sexual health and transitioning from independence to dependence can be on the cancer experience. The other topics discussed showed fertility is not a separate experience but a piece of the entire cancer experience. These interviews unveiled the complexity of the moving through the cancer continuum.

Discussion of Aims

Aim 1 Discussion. The first aim was to describe the views female AYA cancer survivors have toward their fertility and FP decisions.

When the women described views of their fertility, they were uncertain. These study findings reflect those of Zebrack and colleagues (2004) and Halliday, Boughton, and Kerridge (2014) that young women cancer survivors experience feelings of
uncertainty regarding their fertility. Uncertainty was present with many aspects of fertility such as the process to get pregnant naturally or through assisted reproductive techniques and their ability to carry and have a healthy child. Uncertain fertility was difficult to manage and left these women feeling a lack of control and powerless. Very few women underwent testing to determine their fertility status. Young women that never underwent fertility testing, were unsure if or to what extent their cancer treatment affected their fertility. However, they were optimistic that they would be able to conceive naturally if they so desired. Other ways to have a family such as adoption or surrogacy were acceptable and many had thought about adoption or surrogacy as an option if they were unable to conceive.

Family ideals and individual expectations and priorities for their future were considered when making a decision, for those that were told about the potential for fertility impairment with treatment, about FP during cancer diagnosis. Some women prioritized their health and surviving cancer over going through with FP while others prioritized FP and the ability to have a family. Many of the women that decided to forego FP accepted not having biological children and were interested in pursuing adoption or had already adopted. Furthermore, some had family members or friends that adopted or were adopted. Adoption for these women seemed to be more acceptable. The women that underwent FP felt very strongly about having biological children and did everything they could to ensure they had options if they were unable to conceive naturally. Overall, these women viewed their FP decisions positively. Whether the woman decided to forego FP and start treatment right away or delay treatment and undergo FP, it was the right decision at that particular time.
The women that were not given the option of FP or were not told their fertility may be affected by treatment felt their healthcare team made the FP decision for them and that was unfair. These young women wanted the ability to make a decision about their future fertility instead of someone else indirectly making that decision for them. Even if they chose not to pursue FP, it was the decision they made at that time.

**Aim 2 Discussion.** Aim two was to describe the impact fertility and FP had on their lives and their satisfaction with the FP decision and process.

Fertility and FP had an impact on their identity and their relationships through the loss, grief and envy they experienced. Loss resonated with all the young women whether it was a loss of fertility, perceived loss of fertility, uncertain loss of fertility or loss of a partner, potential loss of a partner, and not finding a partner. For these young women infertility, perceived or uncertain fertility was associated with a loss of their female identity which in turn affected their appeal as a partner or potential partner. With this loss came grieving. Grieving did not occur until after treatment was completed but many of the women were not grieving an actual loss of fertility but a potential loss of fertility. The grieving process was unique to each woman interviewed and they were at different stages of grieving at the time of interview. Some had accepted their actual or potential loss of fertility while others were still grieving.

Nearly all the women felt their fertility created stress in their relationships with partners. These findings corroborated with previous findings (Dryden, Ussher & Perz, 2014; Halliday, Boughton, & Kerridge, 2013) that a woman’s fertility status, whether it is known or unknown, impacts intimate relationships. Partnered and single women felt the pressures of societal expectations of women and not being able to or potentially not being
able to provide their partner with a child was hard to accept. Single women felt as though potential partners would see them as less appealing because of the potential fertility issues and the cost to pursue assisted reproductive techniques (ART).

Fertility not only affected intimate relationships, fertility affected relationships with friends and family members. Many women expressed feelings of envy when hearing friends and family members were pregnant. They had a difficult time acknowledging those feelings and some never talked about those feelings with anyone because they felt terrible for feeling that way.

Support from family, friends and faith helped these AYA women conquer cancer especially when it came to all aspects of fertility from making the FP decision to dealing with impaired fertility, loss, grief, adoption, and getting pregnant. Almost all the women talked about the immense support they had from family and friends and were so grateful for everything everyone did for them. Support was attributed to helping these young women get through the hardest days when they wanted to give up. In most cases, faith was a driving force in helping women through the cancer continuum. For the women that identified as Catholic, they struggled making the FP decision since the Catholic Church does not support FP and ART. The women that underwent FP were not supported by their church but still felt the support of their own faith.

Most of the young women were satisfied with their FP decision and the process. The women that pursued FP were very satisfied with their decision and none regretted undergoing FP. On the other hand, women that decided to forego FP did not have any regrets. They accepted their FP decision was the best decision at that particular time. The women that did not have the opportunity to make a FP decision were unsatisfied with the
lack of information they were given but felt their healthcare providers had a reason for not giving them the information such as their doctors were more concerned about saving their patient’s life or their doctors were not aware of the options available for FP. Women that were treated at facilities with extensive fertility resources felt they received the best care compared to other women they knew that were treated at facilities without extensive fertility resources. Many healthcare professionals are concerned with giving young women too much fertility information at the time of cancer diagnosis, however all of the young women in this study felt the more information the better. Even though many of the young women did not focus on fertility until after cancer treatment, those that felt they received extensive information about their fertility felt they knew what to expect when they entered survivorship. They felt follow-up care specifically for fertility and fertility conversations after treatment were lacking and their healthcare providers were reluctant to discuss fertility until they were ready to have children.

Aim 3 Discussion. The third aim was to identify areas of improvement regarding FP across the cancer continuum as described by survivors of adolescent and young adult cancers.

Fertility and FP is an important piece of the AYA cancer care continuum and has implications at various points across the care continuum. The Model for Care Across the Cancer Continuum (see Figure 1) indicates three types of care. Implications for practice at each type of care will be presented in the follow paragraphs.

Implications for practice during cancer diagnosis. Fertility and FP discussions between healthcare providers and patients were not consistently done with the young women in this study. In addition, referrals to fertility specialists were not consistently
provided to AYAs. Having protocols in place that require discussions about the effects of
cancer treatment on fertility and all the options available are important for young women
to make an informed FP decision. Having healthcare professionals educated about
fertility and FP options available to AYAs along with helping AYAs navigate through the
FP process may help AYAs make an informed FP decision.

**Implications for practice during long-term survival.** Survivorship was difficult to
navigate especially when it came to dating and relationships. Single and divorced women
talked about their difficulty in discussing their fertility with new partners and when or is
there a right time to introduce their cancer history in a new relationship. They were
concerned that their partners’ would want biological children and their fertility would
affect the relationship. Women that had a partner at the time of interview and the partner
knew the actual or potential fertility impairment expressed similar concern regarding
whether their partner would want biological children in the future and she would not be
able to conceive.

Provide AYA women with FP resources. Education about fertility and FP options
along with a referral to FP specialist are undoubtedly beneficial. Opportunities to connect
with peers that have or are going through FP decisions could be useful for some AYAs
facing a FP decision. Costs continue to be a barrier for some AYAs as long as insurance
does not cover the costs of FP. However, providing patients with information regarding
organizations that help defray the costs of FP may make FP a reality for AYAs that could
not otherwise afford FP. After cancer treatment, many young women in this study felt
that their healthcare providers did not prioritize their fertility and rarely discussed fertility
even when they would ask questions. Discussing fertility and future family planning,
providing referrals and resources for patients during follow up visits may help calm feelings of uncertainty and allow for an open discussion of options regarding fertility.

The young women in this study commonly discussed their difficulty in accessing resources specifically focused on the unique issues AYAs diagnosed with cancer and AYA cancer survivors face. Resources that inform the young women what to expect during and after cancer treatment help prepare young women for what they may experience. Providing resources that can be accessed by patients that live close to their treatment facility along with resources that can be accessed by patients that live in rural areas is useful.

**Implications for practice during survivor health and resilience.** AYA women diagnosed with cancer experience a multitude of feelings stemming from their cancer diagnosis. Those feelings tend to change as they progress through the cancer continuum. Feelings of grief and grieving were prevalent in the group of eighteen women interviewed for this study. The grieving process was unique to each woman and had no time line. In dealing with the multitude of feelings, support was key. Support helped the women navigate and accept their fertility issues. Much of the support came from family, friends and their faith but they recognized the impact mental health professionals had on them. The young women that saw mental health professionals felt they provided support that was not biased and did not judge them for feeling envy and jealousy toward pregnant women. They were able to validate and accept their feelings without feeling ashamed. Those women that did not see mental health professionals highly recommended AYAs see a mental health professional at some point throughout the cancer continuum.
Therefore, providing referrals to mental health professionals with experience in oncology and fertility may help young women survivors accept their fertility concerns.

Limitations

Although this study provided important insights in the experiences of survivors of AYA cancer regarding fertility, there were limitations in study design. Interviews occurred retrospectively and participants were asked to recall conversations with healthcare providers, family and friends during their cancer experience. The sample was mostly Caucasian, educated women with private health insurance. Therefore, the experiences of the participants may not represent the experiences of survivors of AYA cancer from different ethnic backgrounds, low socio-economic status without private health insurance.

Implications for Future Research

Future research regarding fertility and fertility preservation in AYA women diagnosed with cancer is certainly warranted. This study was cross-sectional, only interviewing the women at one-time point in their lives; future studies would benefit from interviewing the women longitudinally to follow their progression through the cancer continuum and following up with the women at various points throughout the continuum to understand the long-term outcomes. Future studies using decision aids in AYA women diagnosed with cancer faced with a FP decision may be beneficial in guiding AYA women through the FP decision process. Few studies focus on other aspects of FP such as access and utilization of FP resources and success rates of FP. Future research in these areas could further inform healthcare providers and patients when discussing FP options and making the FP decision. Further research on formal survivorship programs and the use of nurse navigators in AYA survivorship programs and how these programs impact
the care and outcomes for AYAs may help healthcare providers better guide AYA survivors.
Appendix A: Screening Form

Participant ID: ____________________________ Date: ____________________________

Age: ____________________________
if <18 or >39, INELIGIBLE

Gender:  ____________ if Male, INELIGIBLE

☐ Male
☐ Female

Do you Speak and Understand English? ____________ if NO, INELIGIBLE

☐ Yes
☐ No

Were you diagnosed with cancer in or after 2007? ____________ if NO, INELIGIBLE

☐ Yes
☐ No

How old were you when you were diagnosed with cancer? ____________ if <15 or >39, INELIGIBLE

☐ Yes
☐ No
Have you completed cancer treatment at least 6 months ago?........if NO, **INELIGIBLE**

☐ Yes

☐ No

Participant Eligible?

☐ Yes

☐ No

Interview Scheduled for:
Appendix B: Demographic Form

Participant ID:

Age:

1. What is your race?
   - [ ] White
   - [ ] Mixed (interracial)
   - [ ] Refusal
   - [ ] Black
   - [ ] Asian
   - [ ] American Indian/Alaskan Native
   - [ ] Other
   - [ ] Hawaiian Native/ Island Pacific
   - [ ] Don’t Know

2. What is your Ethnicity?
   - [ ] Caucasian
   - [ ] Other ______________________
   - [ ] African-American
   - [ ] Don’t Know
   - [ ] Hispanic
   - [ ] Refusal
   - [ ] Haitian/Caribbean

3. What is the Highest Education you have received?
   - [ ] No formal schooling
   - [ ] Completed high school only
   - [ ] Associates degree
   - [ ] Bachelor’s degree
   - [ ] Graduate degree
   - [ ] Don’t Know
   - [ ] Refusal

4. Are you employed?
   - [ ] Yes
   - [ ] No
5. What is your monthly income?

☐ No monthly income  ☐ $601-$800/month
☐ $1-$200/month  ☐ $801-$1,000/month
☐ $201-400/month  ☐ >$1,000/month
☐ $401-$600/month  ☐ Refusal

6. Do you have health insurance?

☐ Yes
☐ No

6a. If YES, what type?

☐ Private  ☐ Don’t Know
☐ Medicaid  ☐ Refused to answer
☐ Medicare
☐ Obamacare

7. Do you have children?

☐ Yes
☐ No

7a. If YES, how many?

8. Did you have any children before you were diagnosed with cancer?

☐ Yes
☐ No

8a. If YES, how many did you have before cancer?
9. Did you have any children after cancer treatment?
   □ Yes
   □ No

9a. If YES, how many did you have after cancer treatment?  ______________________

10. What type of cancer were you diagnosed with?
   □ Leukemia
   □ Lymphoma
   □ Breast
   □ Thyroid
   □ Sarcoma
   □ Brain/CNS
   □ Other  ______________________

11. At the time of cancer diagnosis, what stage was your cancer?
   □ Stage 0
   □ Stage I
   □ Stage II
   □ Stage III
   □ Stage IV

12. What type of treatment did you undergo? (check all that apply)
   □ Chemotherapy
   □ Radiation
   □ Surgery

13. Where did you receive your cancer treatment?  ______________________
Appendix C: Interview Guide

This script will be used to guide the interview. Not all questions will be asked and will be based on the participants’ responses.

To start I will ask you some questions about your cancer diagnosis.

Tell me about your experience of being diagnosed with cancer?

Do you remember being told that your treatment may affect your ability to have children in the future which I am going to refer to as fertility? What do you recall about fertility around the time of your cancer diagnosis? Was it discussed?

Were alternative options to allow you to have children in the future discussed (these options may have been referred to as fertility preservation options)? Tell me what you recall from that discussion.

FP Decision

What was it like having to make a decision about your ability to have children in the future?

Who was involved in this discussion? (i.e., doctors, nurses, parents, family, friends, etc.)

Did you seek additional help or support regarding fertility issues?

Tell me what decision was made and how you came to that decision?

Was cost a factor in the decision?

Knowledge/Beliefs about fertility

Do you know your fertility status?

If yes, have you had testing to determine your fertility status? What type of testing?

If no, do you feel your cancer treatment affected your fertility?

If yes, can you describe what makes you feel your cancer treatment affected your fertility?

If no, can you describe what makes you feel your cancer treatment DID NOT affect your fertility?
Impact of fertility outcome

Have any of these fertility issues impacted your everyday life, such as relationships, particularly with a partner, or your views about future relationships? Tell me more about how this impacted your relationship?

What about your relationships with friends and family?

What about your self-esteem?

Satisfaction with FP decision

Are you satisfied with the FP decision you made? Tell why or why not.

Knowing what you know now, would you change anything regarding the FP decision?

Advice/improvements to FP discussion and decision making

Tell me about the helpfulness of healthcare professionals regarding talking about fertility issues?

Do you feel services can be improved and how?

What would you like healthcare professionals to know about your experience with fertility and FP?

What advice would you give to someone faced with making a decision about fertility?
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