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The Impact of Cancer and Its Treatment on the Sexual Self of Young Adult Cancer Survivors
And as Compared to Their Healthy Peers

A DISSERTATION

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Doctor of Philosophy

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By
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The Impact of Cancer and Its Treatment on the Sexual Self of Young Adult Cancer Survivors

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There is a significant lack of research on the long term effects of cancer treatment on sexuality and intimacy, specifically in those diagnosed as young adults (YA) (18 to 40 years old). Sexuality and intimacy are quality of life issues affected by cancer and its treatments, regardless of age, race, gender, or socioeconomic background. Sexual dissatisfaction, whether physical, psychological, or emotional, not only affects the person being treated for a disease, but also his/her partner and the overall relationship. Although there is substantial literature supporting the challenges in sexual function, fertility, and body image in persons with cancer, there is a significant lack of research on the long term effects of cancer treatment on sexuality and intimacy, specifically in those cancer survivors diagnosed as young adults who are two to five years post cancer diagnosis. Utilizing cognitive theory as the guide, this study sought to explore the differences in this researcher's conceptual model of the sexual self of young adult cancer survivors as compared to their healthy peers (those with no history of a cancer diagnosis).

This exploratory study utilized a mixed-methods research design to study the sexual selves of young adult cancer survivors (diagnosed two to five years ago) and healthy peers. A total of 167 young adults participated in the online survey; 113 survivors and 54 healthy peers. The primary purpose of this study was to investigate this researcher's conceptual

model of the sexual self, and the sexual self of YA cancer survivors; 2 – 5 years post diagnosis as compared to their healthy peers

Findings show that the sexual selves of young adult cancer survivors are indeed different than those of their peers, demonstrating lower sexual esteem, higher sexual distress, and lower sexual function. Additionally, qualitative data demonstrated that health care professionals are not sufficiently addressing the sexual health concerns of young adult survivors. The lack of information provided appeared to be interpreted as dismissive of the importance of their sexuality and sexual health needs. Further, quality of life was lower and psychological distress was higher when a more negative sexual self was present in the survivor.

This dissertation by Sage Bolte fulfills the requirement for the degree of Doctor of Philosophy in Social Work approved by Karlynn BrintenhofeSzoc, Ph.D., as Director, and by Barbara P. Early, Ph.D, S. Michael Plaut, Ph.D., James Zabora, Sc.D. as Readers.

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DEDICATION

I wish to dedicate this dissertation research to all young adult cancer survivors. I offer the commitment that I will continue to strive to make changes in improving the awareness and treatment of your sexual health concerns, both during and after cancer. Thank you for the many lessons you teach me along the way. In the wise words of many of you - Cancer Sucks!

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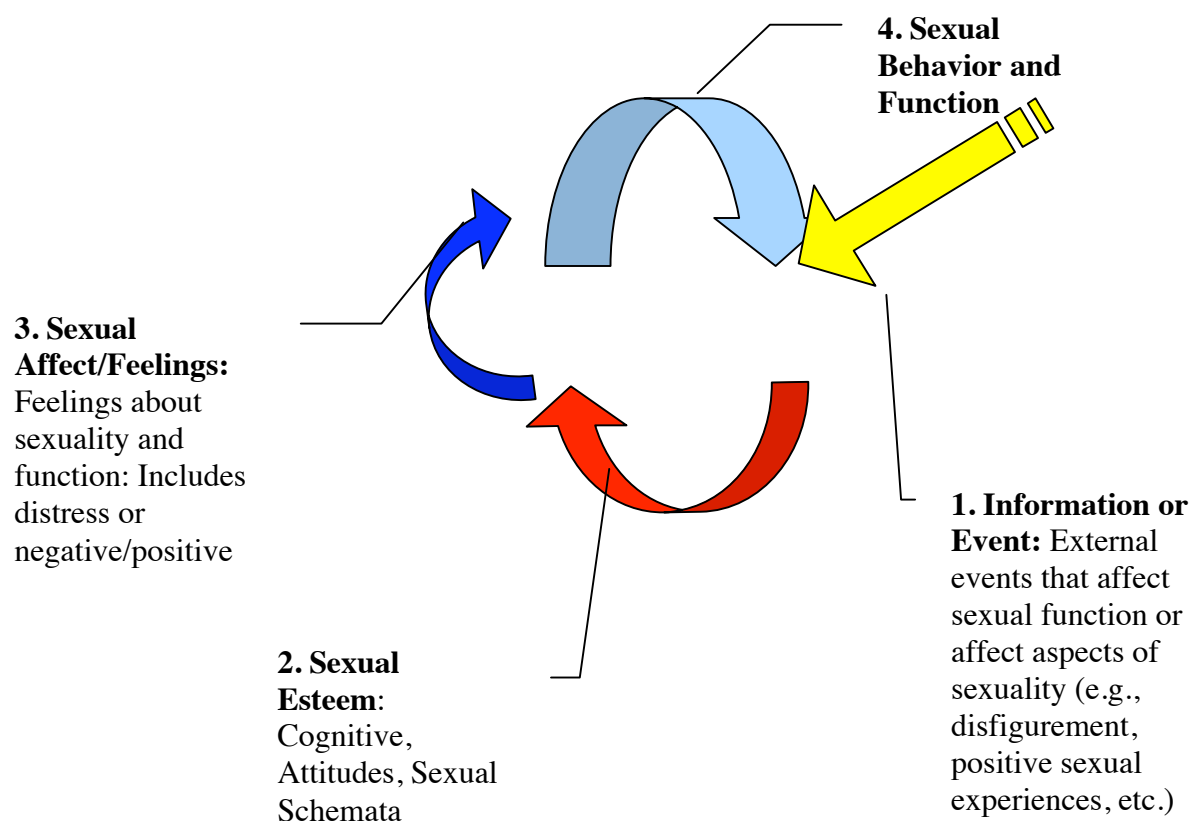
Chapter One

Introduction

Social workers are one of the first line care professionals to conduct a biopsychosocialspiritualsexual assessment with patients who are being treated in both inpatient and outpatient/community oncology settings. With cancer survivorship rates significantly on the rise, the focus of social work practice (along with other disciplines), and research in these areas are growing tremendously. This growth is causing a shift in the focus of patient care to look beyond just the concrete needs of survivors and examine all areas of quality of life (Helgeson, 2005; Katz, 2005; Tan, Waldman, & Bstotick, 2002; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001; Zebrack & Chesler, 2004). As quality of life research has strengthened, one area that is beginning to be recognized is the sexual health needs of cancer survivors (Katz, 2005, 2007; Tan et al., 2003). Although the literature has greatly improved in both the areas of psychosocial and quality of life assessments, including sexual health, most of the research has looked at childhood cancer survivors or adult cancer survivors, with less known about young adult survivors diagnosed between the ages of 15 – 40. In addition, research on sexual health has primarily examined sexual function, fertility, and/or body image (Katz, 2005; Lee et al., 2006; McInnes, 2003; Schover, 2008), and has not focused, as much, on exploring how cancer may affect broader issues related to sexuality. Although all are important, this research hopes to further investigate the sexual health needs of young adult cancer survivors with the introduction and development of the concept of the *sexual self* and explore how the cancer affected sexual self of a young adult may be different than healthy peers. Influenced by previous research, the concept of the sexual self, as defined by this researcher for this study, builds upon the

concept of sexual self schemata (Andersen & Cyranowski, 1994) to involve a working cyclical interaction of sexual esteem, sexual feelings/affect, and back to sexual function and behavior (Figure 1). This dissertation will review current literature on how cancer and the accompanying treatments may influence the young adult cancer survivor's sexual self. Suggestions for future research, policy exploration, psychosocial care needs, and the implications for intervention will be discussed. (Important to note: For the ease of reading, this author has chosen to switch gender possessive pronoun's every other paragraph (unless specifically speaking about a specified gender)).

Figure 1: Conceptual Model of the Sexual Self



Background of the Problem

Approximately 11.4 million people in the United States are cancer survivors (persons living with or previously diagnosed with cancer) (American Cancer Society [ACS], 2007; Center for Disease Control [CDC], 2009). It is estimated that nearly 70,000 young adults will be diagnosed with cancer every year, with death rates higher than those of their younger and older patient counterparts, and quality of life issues, including sexuality, being significantly impacted (Lance Armstrong Foundation Young Adult Alliance [LAF, YAA], 2008). Of these survivors and depending on the diagnosis, 10% to 100% will experience some form of sexual dysfunction (Beckham & Godding, 1990; Derogatis & Kourlesis, 1981; Ofman & Auchincloss, 1992). According to Curtiss and Haylock (2006):

cancer survivors often experience long term changes and obstacles, such as impaired immune response, vital organ dysfunction, hormone changes resulting in infertility, altered sexual function, cognitive changes, ongoing fatigue, depression, anxiety, family distress and economic challenges, to mention only a few. (p. 4)

Common treatments for cancer (e.g., chemotherapy, radiation, and surgery) can have an adverse effect on a person's physiological, emotional, psychological, and sexual well being (Hughes, 2000; Pelusi, 2006; Schover, 1999). Cancer treatments also heighten areas of distress like pain, fatigue, depression, and anxiety (Zabora et al., 2001). Unfortunately, many treatments used to manage the distress of depression, pain, or anxiety also create significant changes in the sexual response cycle, complicating or exacerbating symptoms of sexual dysfunction and how one might view his sexuality (Ananth, Jones, King, & Tookman, 2003; Frumovitz et al., 2005; Hughes, 2000; Pelusi, 2006; Spagnola et al., 2003).

Sexuality and intimacy are quality of life issues influenced by cancer and its treatments, regardless of age, race, gender, or socioeconomic background (Derogatis, 2000; Katz, 2005; Shell, 2002; Zabora, 2004). Sexual dissatisfaction, whether physical, psychological, or emotional, may not only have an effect on the person being treated for a disease, but also on his or her partner and overall relationships (Svetlik et al., 2005). As young adult survivorship rates continue to rise (Adolescent and Young Adult Oncology, Progress Report [AYAO PR], 2006), the sexual self is a critical area to be examined. All of the physical and emotional changes experienced, have the possibility of influencing a young adult's perception of self and how she gains meaning of her world, experiences, and new limitations brought on by the cancer and its treatments.

Among the nearly 70,000 young adults being diagnosed each year, the most common cancers are breast cancer, lymphoma, germ cell tumors (including testicular cancers), melanoma, thyroid carcinoma, sarcoma, cervical carcinoma, leukemia, colorectal cancer, and central nervous system tumors (SEER 17, 2000 – 2003). This population is extremely vulnerable to a sense of hopelessness (Snyder et al., 1997) due to the risk of loss of fertility, dating and disclosure concerns, and problems related to body and sexual self-image. As part of a multidisciplinary team, clinical social workers are trained and expected to address the biopsychosocialsexualspiritual needs of patients. This oncology social worker believes that the sexual self assessment (which includes sexual function, sexual esteem, and sexual affect) has not yet been fully incorporated into the oncology professional's practice. Whether due to fear, discomfort, knowledge, or the belief that another team member will address sexual

health issues, sexual concerns are often being overlooked in the assessment of patients (Cagle & Bolte, 2009; Mick, 2007).

Several recent studies explored the experience of young adult survivors of childhood cancers (Roberts, Piper, Denny, & Cuddback, 1997; Zebrack, 2008; Zeltzer, 1992), and one recent paper on sexual functioning in childhood cancer survivors (Zebrack, Foley, Wittmann, & Leonard, 2009). However, few researchers have explored the experience of individuals diagnosed as young adults and none that specifically look at the possible relationships between a cancer diagnosis and a young adult cancer survivor's sexual self. This study seeks to further the knowledge base and understanding of the cancer experience on young adult cancer survivors and work towards the development of assessment and evaluation of these patients.

Theoretical Framework

Utilizing cognitive theory as the guide, this research seeks to explore whether there is distress and disruption in the sexual self of young adult cancer survivors as compared to their healthy peers. The theory posits that through experience people develop memory structures, known as schemata, of elements that conceptually relate and that guide the processing of information. Important among these schemata are self schemata that incorporate the belief(s) and ideas that a person may have about himself. Individuals contain many selves and access them when making sense of a particular event, or situation (Berlin, 2003; Markus & Nurius, 1986; Nobre & Gouveia, 2000). Individuals may also have competing schema such as "I'm broken" (when referring to how he thinks about himself after cancer), and another of "I can manage hard things" leading him to believe that he is able to manage the thoughts of "being broken", and find ways to make sense of his new normal after cancer. For example, a young

adult who has had cancer may access the schema of “cancer survivor” when visiting her oncologist, but the schemata of an “artist” and “teacher” when at work as an art teacher. In her role as “cancer survivor” she may retrieve the belief that she is incompetent in retaining the information her doctor gives her and therefore feels anxious at all of the appointments. However, in her role as “artist and teacher” she may recruit the belief that she is creative and capable and therefore, has feelings of calm as she is able to make her lesson plans each day without distress.

In the development of the conceptual model of the sexual self, information was gleaned from terms on sexuality and sexual self schema. Henson (2002) describes sexuality as encompassing body image, ability to interact in a sexual manner with a partner or by oneself, communication of one’s sexual needs, sexual functioning, desirability, femininity/[masculinity], and ability to bear children. The sexual self schemata in previous research has been conceptualized as a cognitive framework for sexual aspects of oneself and are “products of past experience, manifest in current experience, influential in the processing of sexually relevant social information” (Andersen, Cyranowski, & Espindle, 1999, p. 658) and can influence sexual behavior, responses, and affect (Andersen & Cyranowski, 1994). The sexual self, as all selves, can be flexible, cohesive, differentiated, and multifaceted, and will gain knowledge and adapt based on experiences in the environment and relationships.

Berlin (2002), who developed the Cognitive Integrative Perspective (C-I), reports that people who identify a greater number of self-concepts and relative independence among them can better adapt and withstand the emotional and physical consequences that negative life events may create. C-I claims that not only is an individual’s meaning making influenced by

his thoughts, but also how he makes meaning of the impact of the life events. The sexual self is related to intrapersonal and interpersonal aspects of sexuality. Cognitive theory and C-I recognize the role of subjective interpretation, however, C-I also acknowledges the uninterpreted impact of objective information. The three domains of the sexual self, as conceptualized in this study (sexual function, sexual esteem and sexual affect), are not only influenced by the objective information about the disease that confronts the cancer survivor, but also by the meaning in which he makes of the information. The diagnosis and treatment of cancer in young adults are often life changing events with many of the treatments having lifelong consequences that the sexual self must absorb. If the young adult interprets the information in a negative way, this may increase negative thoughts, sexual distress, and sexual dysfunction (Figure 2).

Taking a cognitive-integrative approach, how the young adult responds to the diagnosis and the changes in his sexual function are influenced by how she continues to make meaning of the experiences in the present. A young adult's relationship status, previous sexual experiences, self-esteem, physical health, resources, and understanding of cancer and its possible adverse effect on sexual function all influence her sexual self – positively or negatively.

Interest in the Problem

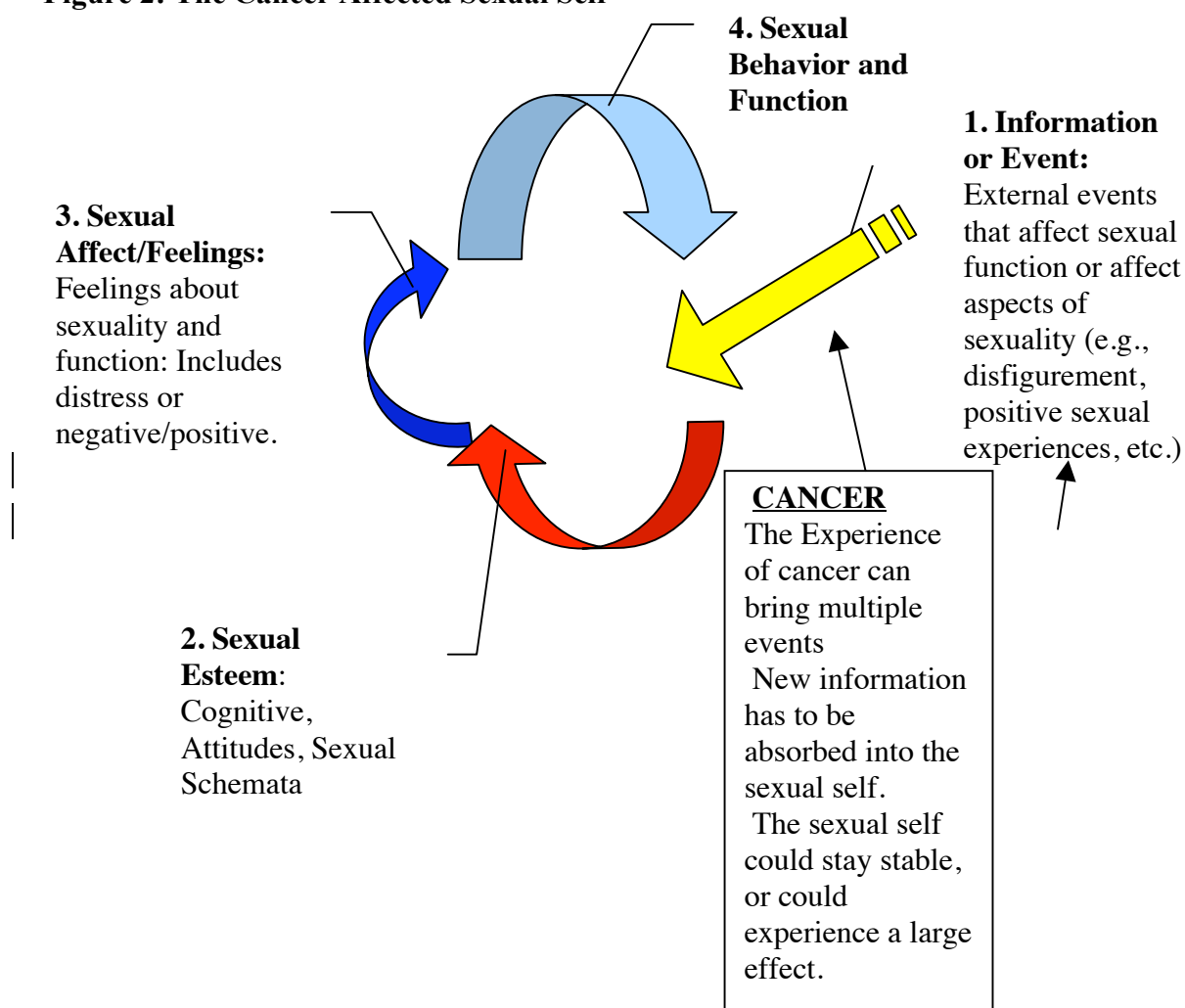
The Association of Oncology Social Work [AOSW] states:

Oncology social work is the primary professional discipline that provides psychosocial services to patients, families and significant others facing the impact of a potential or actual diagnosis of cancer....Psychosocial services provided by oncology social workers

include individual, family and group counseling, education, advocacy, discharge planning, case management and program development. These services are designed to maximize the patient's utilization of the health care system, foster coping, and mobilize community resources in order to support optimal functioning. (AOSW, para 1 & 3, 2009)

The cancer literature supports the idea that sexuality is an integral part of a patient's quality of life (Katz, 2005, 2008; Schover, 1998, 2008; Schover et al., 1995) and, therefore, addressing sexuality may be a significant part of a patient's "optimal functioning".

Figure 2: The Cancer Affected Sexual Self



As an oncology social worker, this researcher has seen firsthand the importance of helping patients and their loved ones improve all aspects of their quality of life, both during and after cancer. This seems especially pertinent to young adult cancer survivors in their particular phase of the life cycle. These young people are in the process of seeking autonomy, establishing their place in a community, graduating from college, starting a career, creating families, or long term partnerships – all directly or indirectly influenced by a diagnosis of cancer. As this researcher has witnessed in the young adult support group she facilitates, young adults are also in the process of developing a sexual self, which includes exploration of sexuality, strengthening sexual confidence and esteem, recognizing that sexual preferences may change over time, and building long term intimate relationships. Cancer and its treatments interrupt this exploration and development, leaving many unsure of how to make sense of the changes. Young adults are left feeling challenged to redefine what may be their “new normal”. Unfortunately, few oncology health care professionals address the issue of sexuality with patients during and/or after treatment, unless the patient brings it up, or fertility issues need to be addressed. It is this researcher’s belief that every person - young or old, partnered or single, with cancer of a sex organ or not - be assessed and educated on the possible adverse effects that cancer and its treatments may have on his/her sexual health.

Purpose of the Study

In this researcher’s professional experience young adult patients’ sexuality is overlooked in the assessment of quality of life issues in treatment and survivorship clinics. Too often it seems the focus on treatment of young adult survivors is “cure” and neglects the secondary and late effects like infertility, osteoporosis, chronic pain, disfigurement, and

sexual health which could have potentially devastating implications on a persons' distress levels and quality of life and can affect the sexual dimensions of their sense of self. The purpose of quantitative portion of this study was to apply Berlin's (2002) cognitive-integrative conceptual framework to develop the concept of the sexual self. Additionally, it was intended to test the possible ways the experience of cancer may impinge on the sexual self of young adult cancer survivors. Furthermore, it was intended to explore whether there was a possible relationship between the cancer-affected sexual self on psychological distress and quality of life in these young adults. The following hypotheses were explored: **H1:** Controlling for current age, young adult cancer survivors will identify more negative sexual selves than their healthy peers; that is they will have lower sexual functioning, lower sexual esteem, and higher sexual distress. **H2:** Controlling for current age and age at diagnosis the more negative the sexual self in a young adult survivor, as indicated by lower sexual functioning, lower sexual esteem, and higher sexual distress, the higher the psychological distress and the lower the overall quality of life. The aim of the qualitative portion of this study was to include the perspectives of a small number of the young adult survivors to enrich the understanding of how cancer affects the various domains of the sexual self and how they perceive the effects on aspects of their quality of life.

Significance of the Research to Social Work

Understanding the possible influences that cancer and its treatments may have on the sexual self of young adult survivors is an important aspect of survivorship and quality of life. The measurement and recognition of the sexual self and quality of life in both young adult cancer survivors and in a comparison group of healthy peers are important steps to improving

the understanding of the relationship between a cancer diagnosis and the possible disruptions to the sexual self. This new knowledge will help develop models to support young adults who have been diagnosed with cancer with the goal of increasing quality of life.

This study will further the knowledge base and understanding of the cancer experience of young adult survivors and could assist in the development of specific assessments and evaluation of these patients. The information gathered could greatly influence the way that young adults are approached and quality of life measures selected for use in survivorship clinics by oncologists, nurses, psychologists, psychiatrists, social workers, child-life workers, or by their primary care physicians in follow-up care. Implications for training seminars might also be identified to further the education of health care professionals on patients' sexual health and sexual needs. The data gathered could also lead to further research regarding the need for proactive care around the sexual self and the possible relationships between several aspects of the sexual self, quality of life, and psychological distress. The differences identified between young adult cancer survivors and healthy peers could lead to policy changes in the sexual health and distress screening and assessment of newly diagnosed and long term survivors within the hospital and clinic settings.

Plan of Chapters

This study is presented in five chapters. Chapter One presents an introduction to the research area and problem to be addressed, the weaknesses of the current literature as well as its significance to the profession of Social Work. Chapter Two continues to address the literature and gaps in the literature on the topics of the young adult cancer survivors and the sexual self, as well as the theoretical framework that supports the research questions. Chapter

Three provides the methodology used to gather and analyze data; including study design, hypotheses, description of the study population, data collection, and study scales as well as an explanation of the data analysis process. Chapter Four addresses the qualitative and quantitative findings, along with how the findings relate to the hypotheses. In conclusion, Chapter Five presents a brief summary of the study and conclusions to be drawn from the study's data, including suggestions and implications for future research.

Chapter Two

Review of the Literature

Important Definitions

The definitions listed below are terms used throughout this paper, and will be helpful to the reader prior to continuing.

Survivor/ Survivorship/ Patient.

Survivor/ Patient.

One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life. Therefore, a survivor could be someone who has no evidence of disease or is living with cancer. (National Cancer Institute (NCI) dictionary, n.d.)

Survivorship.

In cancer, survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience. (NCI dictionary, n.d.)

Cancer.

A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer. Carcinoma is a

cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukemia is a cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system. Central nervous system cancers are cancers that begin in the tissues of the brain and spinal cord. [Cancer is] also called malignancy. (NCI dictionary, n.d.)

Late Effects.

“Late effects can be defined as side effects of treatment that last months to years (some permanent) as a result of the cancer treatment and can include physical and mental problems as well as secondary cancers” (NCI dictionary, n.d.).

Cancer Treatments: Chemotherapy, Bone Marrow and Stem Cell Transplant, Surgery, Radiation Therapy.

Chemotherapy.

“Treatment with drugs that kill cancer cells” (NCI dictionary, n.d.). Drugs that kill all rapidly producing cells including cancer cells, as well as blood, hair, and skin cells. These treatments can be administered through an infusion or in pill form. If offered by infusion, it is typically connected to a central line or port/port-a-cath which is an “implanted device through which blood may be withdrawn and drugs may be infused without repeated needle sticks” (NCI dictionary, n.d.).

Stem Cell Transplant.

“A method of replacing immature blood-forming cells that were destroyed by cancer treatment. The stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells” (NCI dictionary, n.d.).

Bone Marrow Transplant.

A procedure to replace bone marrow that has been destroyed by treatment with high doses of anticancer drugs or radiation. Transplantation may be autologous [an individual's own marrow saved before treatment], allogeneic [marrow donated by someone else], or syngeneic [marrow donated by an identical twin]. (NCI dictionary, n.d.)

Surgery.

“A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.” (NCI dictionary, n.d.)

Radiation Therapy.

The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiotherapy. (NCI dictionary, n.d.)

Sexuality, Sexual Health, and the Sexual Self.

The World Health Organization [WHO] (2002) provides two helpful working concepts of Sexuality and Sexual health.

Sexuality.

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (¶ 8)

Sexual health.

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. (¶ 9)

Sexual self.

The sexual self encompasses body image, ability to interact in a sexual manner with a partner or with oneself, desirability, femininity/masculinity, and ability to bear children (Henson, 2002). The sexual self, as it is used in this study, is a concept developed by this researcher and influenced by previous research. It expands the concept of sexual self schemata to involve a working interaction of sexual esteem, sexual affect, and sexual function/behavior. (See Figure 1)

Sexual Esteem: Sexual esteem, or how one thinks about ones sexual self, is formulated as a set of sexual self-schemata (Andersen & Cyranowski, 1994). This sexual self-esteem includes schemata of judgments about oneself in the area of sexuality, values, and cultural influences that have created and influenced how an individual evaluates himself as a sexual being. Our sexual esteem or schemata about our sexuality (e.g., “I am not attractive and will never be,” “I am loveable and desirable,” or “Being lesbian/gay is not okay”) are learned memory patterns (memories established from previous experiences and information that shape and influence the way we interpret current information) and attitudes developed through repeated encounters with similar experiences, perceived good or bad sexual experiences, and/or religious experiences or beliefs.

Sexual Affect: An emotional response to the way one thinks about themselves as asexual being – this response can be positive or negative. Sexual distress is experienced in response to negative thoughts about one's sexual self-worth; how one feels about sexual function or dysfunction; anxiety, depression, excitement, and sexual pleasure that arises from sexual function and dysfunction.

Sexual Function and Behavior: Sexual behavior or sexual function expresses the sexual thoughts and feelings through behaviors like kissing, having sex, masturbating, putting on makeup, and being intentional about looking nice. Sexual function would be the ability to experience the various phases of the sexual response cycle.

Young Adult Survivor

An individual diagnosed with cancer between the ages of 15 and 38 and is now between the ages of 18 to 40. For the purpose of this study, this researcher is only looking for young adult survivors who are 2 to 5 years from initial diagnosis.

Review of the Literature

More than 11 million people in the United States are cancer survivors, and each year 70,000 young adults between the ages of 15-39 are diagnosed with cancer, representing about six percent of all new cancer diagnosis (ACS, 2007; AYA0 PR, 2006; NCI, 2006).

Currently, more than one in every 900 persons in the United States between the ages of 20 and 45 years of age are survivors of childhood and adolescent cancer (ACS, 2008).

Treatments and early detection have greatly improved survival rates with greater than 60% of adult oncology patients expected to live five or more years after diagnosis (ACS, 2007).

However, cancer incidence among individuals aged 15 – 29 have quickly risen in recent years, greater than younger children and older adults and rates of survival for this population have been below average when comparing to other populations (Bleyer, 2007).

Late effects of cancer treatment such as early menopause, increased risk of osteoporosis, cognitive delays or defects, infertility, heart failure, hearing loss, second cancers, and chronic fatigue are now being identified in the adolescent and young adult population (AYA0 PR,

2006; Evan et al., 2006; Gotay et al., 1998; Hampton, 2005; Zebrack et al., 2006). Psychosocial late effects, such as changes in perceptions of body image and self-esteem, relationship and social development, and employment challenges, have also been explored; however, the majority of the research on the psychosocial late effects has focused on the adult population, and the literature is limited in regards to those diagnosed as adolescents and young adults (Elad et al., 2003; Evan, 2006; Manne et al., 1998; Zebrack et al., 2006). Although there is more literature on the effects of cancer and its treatments on the biopsychosocial and fertility issues of younger patients, there has not been enough attention paid to the interaction of a cancer diagnosis on all aspects of sexuality in this population.

Some of the challenges surrounding research on cancer and sexuality, is that sexuality, sexual health, sexual self, etc. are not well-defined concepts prior to doing the research. Monga (2002) claims that it is essential that researchers examine and understand sexual behavior, including the act of sexual play with oneself or others, to truly understand the possible influences cancer and its treatment have on sexuality, claiming this has not been studied in persons with cancer. This research hopes to more clearly define the sexual self and identify possible relationships between a cancer diagnosis, the sexual self and perception of quality of life to inform future research.

Young adults, sexuality, and illness

Although some cancers are treated as a chronic disease and many of the late effects of cancer require long-term management, a diagnosis of cancer has different ramifications (socially and physically) than other chronic diseases. Therefore, although it is helpful to

identify some research on chronic illness and young adults it is important to recognize that the information may not be fully applicable to cancer survivors.

A cancer diagnosis is often not visible to the person on the street a year after treatment is complete. Hair loss from the chemotherapy has grown back, the mediport (a temporary device inserted in the chest or arm for the administration of IV chemotherapy) has often been removed, the scars are less noticeable, and the skin has almost healed from radiation. Many of these immediate visible effects of cancer and treatments start to become invisible after the treatments are completed. However, late effects often impact the individual months to years after a diagnosis. There is a substantial amount of literature on living with a chronic illness as a young person, but very little literature on life “after cancer” for the young adult survivor as far as the short and long term ramifications of treatment. The societal acceptance of, or discussion on, living with diabetes or asthma, for example, is much more prominent and better understood. However, the relationship between having cancer and its continued influence(s) on the present is not as well discussed or understood.

Society is generally uncomfortable with the notion that people who are ill or disabled might still be interested in, or engage in sexual behavior. According to Milligan and Neufeldt (2001) many persons with disabilities [including chronic diseases] are sexually disenfranchised by a society that “inaccurately perceives them as asexual beings” (p. 91). While some sexual activity may not be possible or may have to be adapted as other aspects of living with chronic illness intervene, sex may remain a significant part of day-to-day life, even for men and women who are seriously disabled by illness (McInnes, 2003). For example, in a first of its kind study exploring the basic issues of sexuality in patients with non-invasive

mechanical ventilation (NMV) for chronic respiratory failure as compared to healthy peers, Schonhoffer et al., (2001) found that although sexual function may be impacted by the illness, desire for sexual intimacy and ways to stay sexually engaged (e.g., sexual fantasy) are still prevalent and desired. Of the 383 qualifying patients, 208 responded to open and close ended questions on their experience of various aspects of sexuality and living with NMV. Forty-six percent did not change their level of sexual activity, 36% were less active sexually (but still had significant desire to find ways for intimacy), and 13% were more active. The average frequency of intercourse was about five times per month. The study concluded that even when a significant degree of disability is present, the desire for and experience of sexual activity persists (Schonhoffer et al., 2001).

Much is to be desired for the literature on sexuality and chronic illness and disability (Milligan & Neufeldt, 2002). In general, it appears that people with any type of chronic physical or mental illness have to fight against a stigma that they are not “supposed to be” sexually interested or sexual beings. In a thorough examination of the literature, Milligan and Neufeldt (2002) reported that some of the literature around persons with disability (physical or mental) supports the idea that they are not able to be as “sexually marketable than their able bodied peers” (p. 99) and are, in a sense, considered “damaged goods” by society and possibly by themselves. Therefore, if a young adult views himself as disabled, one might assume that his social supports and/or potential peers and mates, may view him as asexual or less than capable of having intimate relationships. Historically, adolescents and young adults with medical illnesses have been viewed as much younger than they actually were (infantilizing them), having greater dependence, and asexual and have been found to have

greater social isolation than their peers with more limited opportunities for psychosexual development (Lock, 1998; McCabe & Cummins, 1998; Suris et al., 1996). During adolescence and early young adult years a significant part of self-esteem is derived from sexual identity and, therefore, a diagnosis of a significant illness as an adolescent or young adult may challenge a positive sexual identity (Eccles et al., 1993). Young persons with chronic illness often face difficulties in starting and maintaining relationships and experience ongoing problems with sexual function (McInness, 2003; Schover, 1988). For example, studies have reported that there is a lack of intimate relationships and relationship difficulties in young adult (males) with Juvenile Idiopathic Arthritis, with 58.3% reporting disease related sexual problems (Packham & Hall, 2002). The growing importance of peer relationships, changing relationships within the family, and the expansion of social networks are key pieces of adolescent and young adult social development. For the young adult, “sexuality becomes central, introducing intense physical sensations, new types of intimacy, different roles in peer groups, and important health considerations” (Davis & Vander Stoep, 1997, p. 402).

In a study examining the identified needs of young adults cared for by a diabetes center, one of the top three educational services identified as needed was information on sexual health (Scott et al., 2005). However, there is much evidence demonstrating that few health care providers are addressing sexuality and sexual health with young people who have a chronic illness, as reported by the lack of documentation in case-notes of adolescents with chronic illnesses (Robertson et al., 1996). Such data is worrisome in that many young people with chronic illnesses and/or physical disabilities are reported to be at least as sexually active as their peers (McDonagh, 2006). It is this researcher’s experience, and the experience of

others, that older adolescents and young adults who have “fought” a life threatening illness such as cancer, or have other life limiting diseases, can be greater risk takers in the areas of sexual behavior and other risky behavior (Hollen & Hobbie, 1996; McDonagh, 2006).

Hollen and Hobbie (1996) found that poor quality decision making was significantly associated with higher levels of substance use risk behaviors for teen cancer survivors.

Therefore, although sexual practices have not been researched, some may be making riskier decisions when it comes to their sexual health practices. McDonagh (2006) reported that due to some of the maturational challenges, young people with a chronic illness may engage in risky behaviors, such as unprotected sex, as a means of achieving developmental goals like independence or peer acceptance. For the older young adult, behaviors might occur such as dating a person that they might not have dated prior to cancer but now think “I’m damaged goods, who would want me now”. This social worker has experienced several young adult cancer survivors choosing to engage in unprotected sex due to being told they were infertile – completely disregarding the fact that they were still susceptible to sexually transmitted infections (STI’s).

Many of the studies on sexuality in younger populations have explored more of the psychosocial effects, however, these studies on “the implication of chronic medical conditions, such as childhood-onset cancer, cystic fibrosis, and epilepsy, provide examples of ways these types of illnesses may affect psychosexual development” (Lock, 1997, p. 341). A variety of studies have examined the relationships between cancer and various psychosocial issues (e.g., social adjustment, psychological distress, familial stress/support, etc.) of adolescents, and found that they develop problems with body-image disturbance and poorer

sexual adjustment compared to their healthy peers (Madan-Swain et al., 1994). Key sexual issues for older adolescents in the late phase of sexual development and exploration (aged 18 and older), while focused on developing more intimate relationships, are concerned about decreased life span, fertility, anxiety about transferring dependency needs from families onto intimate partners, and anxiety about a possible genetic link or mutation in passing this cancer on to their offspring (Lock, 1998). Because many of these young adults have to go back to depending on their family's support for practical, emotional, and financial needs, they may not be able to fully develop an adult role required for sexual intimacy, or may revert back to old patterns they once had when reliant on family. This decrease in development may be especially true for the younger young adult diagnosed in their late teens. However, the older young adult may struggle with maintaining his role with his wife (both sexual and non-sexual) if his mother has moved in to help.

Although there is literature to support the idea that having a chronic illness during one's adolescent and young adult years may influence certain or all parts of the sexual self, there is little known on the long term relationship challenges between cancer and its treatment on sexuality in this population. Living with a chronic illness, or late effects from a cancer diagnosis – whether physical or emotional – may all directly or indirectly affect sexual performance abilities and sexual choices, as well as how an individual views her sexual self. This dissertation will further explore how a diagnosis of cancer may have long lasting effects on how survivors may identify their sexual selves as compared to healthy peers. In order to do so, one must first understand the sexual response cycle.

The sexual response cycle and cancer

Depending upon diagnosis and treatments, significant sexual disruptions can occur in 10% to 100% of survivors (Beckham & Godding, 1990; Derogatis & Kourlesis, 1981; Ofman & Auchincloss, 1992). This can be experienced in some form of change or interruption to one or several parts of the sexual response cycle, including sexual pain, with the most common complaint by women and men being the decrease in libido (Andersen, 1985; Andersen, 1990; Derogatis, 1981; Frumovitz et al., 2005; Lamb, 1995; Lock, 1998; Syrjala et al., 1998). Hormonal changes, low iron, side effects of chemotherapy and radiation, vascular, or nerve damage have also been linked to alterations in sexual function in persons who have or have had cancer (Hughes, 2000; Penson et al., 2000; Schover, 1999). In order to best understand how cancer and its treatments may interact with the sexual self, it is important to first understand the “sexual response cycle” responsible for sexual function.

The sexual response cycle is a phrase used to describe the emotional and physiological processes the body goes through as a person becomes sexually aroused and participates in sexually stimulating activities. The sexual response process is unique to each individual, with the personal experience varying, both within each sexual occurrence, and in systemic terms. Cancer treatments, more often than cancer itself, have the potential to disrupt one or more phases of the sexual response cycle (Tierney, 2008).

There are several proposed models of the sexual response cycle, and they continue to evolve. Kinsey’s introduction of research on sexual function was the first to expand our understanding that the sexual response cycle is a complex physical and emotional reaction (Kinsey et al., 1948). Out of Kinsey’s research, Masters and Johnson (1966) identified four

phases of sexual response; excitement, plateau, orgasm, and resolution. Kaplan (1979) later modified to three-stages of desire, excitement, and orgasm. Zilbergeld and Ellison (1980) introduced the idea of an additional phase, to include how one thought about (or cognitively appraised) the sexual encounter. When discussing sexual function, this paper will assess how desire, arousal, orgasm, and appraisal may be influenced by cancer and its treatments with the acknowledgement that men and women may experience these phases differently.

Recently, there has been further acknowledgement that the male and female sexual responses may be different (Basson, 2001; Whipple & Brash-McGreer, 1997). The female sexual response cycle is now commonly recognized as more circular than linear (Basson, 2001), where the male sexual response cycle still tends to be seen more as a linear response (see Figures 3 & 4). The non-linear, circular model proposes a woman's sexual desire and response is influenced by numerous psychosocial issues (intimacy with partner, how she feels about herself, previous negative sexual experiences, etc) and she may go in and out of a response phase, or skip one of the phases all together depending upon her ability and/or needs. Skipping any phase does not necessarily mean that they are experiencing sexual dissatisfaction or dysfunction. The linear male model, although taking more into account for the emotional and or the evaluation of a sexual event, is more focused on the succession of stages: desire (libido), excitement (arousal), plateau, orgasm, resolution (reflection/satisfaction). Cancer and its treatments (whether directly or indirectly) seem to most strongly influence (often decreasing) desire and can interrupt or change the excitement and orgasm phase. Although researchers continue to refer to the male's sexual response as

being linear, it is this researcher's belief that males are just as likely to experience the circular model as well.

Basson (2001) reports that for women, completing, skipping, or not completing one or all of the phases does not necessarily lead to distress or discouragement around sexual function but rather the emotional and cognitive interpretation of the disruption in the cycle can lead to distress and dysfunction. In other words, a woman may not feel any sexual desire initially but desire for intimacy with her partner and therefore may be able to experience pleasure in touch or other types of sexual play, still reach an orgasm and be very satisfied despite the initial lack of desire. Another woman may have the same experience but find herself unable to experience pleasure in any type of sexual play because she is so distressed about not having sexual desire first. This may be true for some men as well however, many studies have shown that good erectile function for men is very important in a man's desire for sexual intimacy and his sexual and self-esteem (Althof et al., 2005; Dean et al., 2006).

Figure 3:
Sexual Response Cycle – linear model

(1) Sexual Desire/Libido - This phase consists of fantasies about sexual activity and the related desire for it. The DSM-IV disorders related to this phase are Hypoactive Sexual Desire Disorder and Sexual Aversion Disorder.

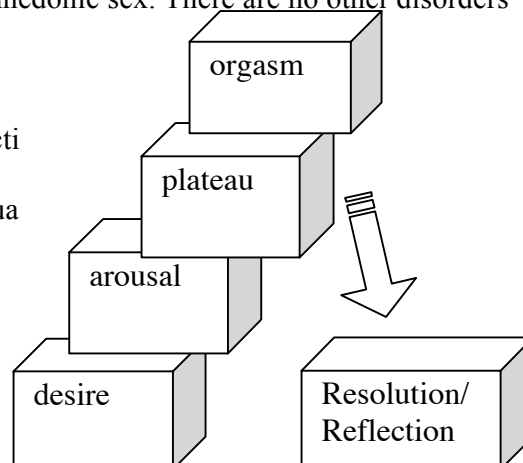
(2) Sexual Excitement - This phase consists of a subjective sense of sexual arousal and pleasure and the accompanying physiological changes. The major changes in the female consist of vasocongestion in the pelvis, vaginal lubrication and expansion, and swelling of the external genitalia. The major changes in the male consist of penile tumescence and erection. The related DSM-IV disorders are Female Arousal Disorder and Male Erectile Disorder.

(3) Plateau – The highest point of sexual excitement, which extends to the brink of orgasm. The vagina continues to swell from increased blood flow and the clitoris becomes highly sensitive. The man's testicles are withdrawn up into the scrotum. Breathing, heart rate and blood pressure continue to increase and muscle spasms may begin in feet, face and hands along with tension increasing in the muscles.

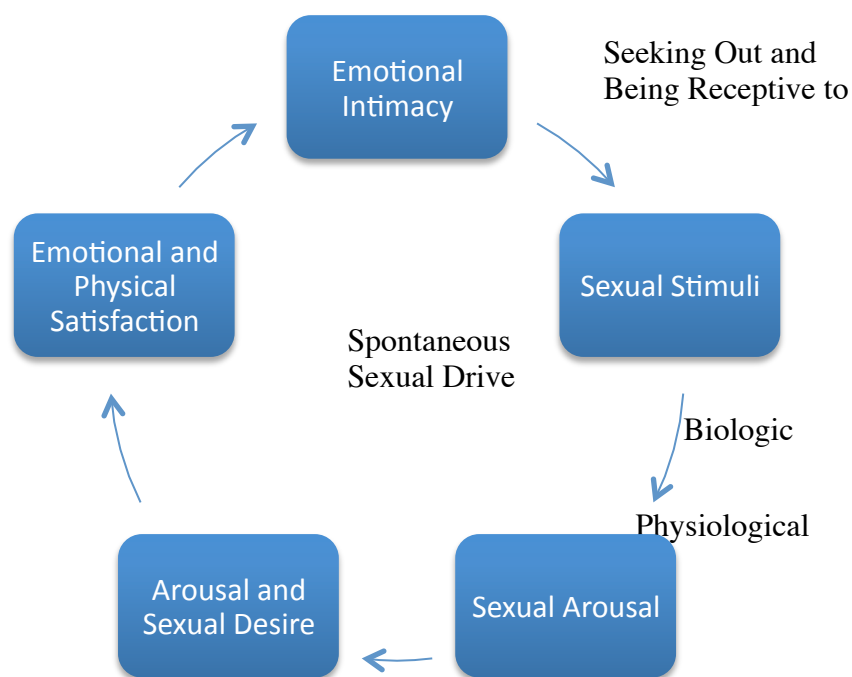
(4) Orgasm - This phase consists of a climax of sexual pleasure with accompanying rhythmic contractions and the sudden forceful release of sexual tension. In the female, there are vaginal contractions. In the male, there are rhythmic contractions of the muscles at the base of the penis. Ejaculation of semen may also follow. The related DSM-IV disorders are Female and Male Orgasmic Disorder and Premature Ejaculation.

(5) Resolution/Reflection/Satisfaction - The fourth and final phase, consists of a sense in general relaxation, well-being, enhanced intimacy, muscular relaxation and often fatigue. During this phase, males are physiologically refractory to further erection and orgasm for variable periods of time. In contrast, females may be able to respond to additional stimulation almost immediately. Satisfaction is also an important part of this phase. Did the individual feel satisfied after a positive experience? Some may experience no satisfaction but be able to physically perform, which may be referred to as anhedonic sex. There are no other disorders related to this phase.

Adapted from
http://www.psychtreatment.com/sexual_dysfunction.htm and The Cleveland Clinic,
http://myclevelandclinic.org/healthy_living/sexual_health/healthyc_hic_the_sexual_response_cycle.aspx



**Figure 4:
Basson's Non-Linear Model of
Female Sexual Response**



Adapted from: Basson, R. Female sexual response: the role of drugs in the management of sexual dysfunction. *Obstetrics and Gynecology*, 98, 350 – 353.

Libido is defined as sexual desire (NCI, 2009). Many individuals confuse sexual desire as sexual function or arousal, and although desire and arousal can simultaneously exist, they are also separate responses.

Theorists and researchers in the area of sexual desire have used two main frameworks.

The first and most common assumes that sexual desire is an innate motivational force (e.g., an instinct, drive, need, urge, appetite, wish, or want). The second framework emphasizes the relational aspects of sexual desire, conceptualizing desire as one factor in a larger relational context. (DeLamater & Sill, 2005, p. 1)

Desire encompasses the physiologic, behavioral, and relationship components, and are unique to each individual and therefore, desire is complex and not fully understood (Tierney, 2008). Desire has been linked to thoughts (Carey, 2006) and when thoughts about oneself, sexual activity, or partner are negative (e.g., “She won’t find me attractive”) desire can be decreased. If one exhibits positive thoughts about body image, sexual activity, and or the desire to have desire, this person may be more likely to experience an increase in desire.

Cancer treatments, directly and indirectly, influence desire. Therefore, desire can be altered by the many emotional tolls that a diagnosis carries, as well as the physiological problems created from the treatments and ongoing therapies. For example, a man’s negative thoughts about himself as a sexual being can lead to lower desire or influence his desire to be sexually intimate, witnessing the emotional toll on desire. In addition, physiologically a man’s testosterone level may have been influenced by treatments and therefore desire has been lowered.

Arousal and arousal disorders can be subjective and/or physiological (DSM-IV) (American Psychiatric Association, 2004). Subjective arousal includes the experience of excitement and pleasure often in connection with sexual thoughts or feelings and may be referred to as feeling “turned on”. Physiological sexual arousal includes, for example, the

increase of blood flow to the genitals, which causes an erection, the clitoris to engorge, the vagina to deepen and widen, and vaginal lubrication to increase. The physiologic sexual arousal changes that occur are guided by the central nervous system (CNS). Therefore, if the cancer affects the CNS or the Autonomic Nervous System, sexual arousal may not be possible.

Orgasm is often the final part of the sex act, as a physical and often emotional response to sexual stimulation, which involves contraction of sexual organs and a sudden release of endorphins, leading to a feeling of pleasure (NCI, 2009). In males, orgasm usually occurs with the release of semen. Reflection, which in a linear model comes after orgasm and in a non-linear model can occur at any phase, is the interpretation or internalization of the sexual experience as positive, negative or neutral and can influence future sexual behaviors.

It is not necessary to complete each of these phases in order to have a satisfying sexual response. For example, a woman can have low desire, experiences subjective arousal after sexual play with her partner and does not experience an orgasm but still reflects back on her experience as positive and pleasurable. It is how the individual thinks about the experience (reflection) and response that leads to the assessment of whether the physical sexual dysfunction is or is not an emotional problem or distressing.

The sexual response cycle is somewhat limited to focusing on sexual activity and response, however, as discussed in this paper the sexual self is a broader concept and the sexual response is just one aspect. Cancer treatments have the potential to interrupt the sexual response cycle and cause sexual dysfunction. Sexual dysfunction, as described by The Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) (American

Psychiatric Association, 2004), is a disorder that may affect one or more phases of the sexual response cycle and negatively influence sexual functioning, resulting in psychological distress or stress within relationships. Sexual pain disorders are also a part of sexual dysfunction, such as vaginal stenosis (the narrowing of the vaginal canal) or dyspareunia (painful sexual intercourse), which some cancer survivors will experience.

Among many other responses, men can experience erectile dysfunction, infertility, body image concerns as it relates to weight changes, hair loss, and surgical scarring, all as a result of cancer, along with concerns around disclosure or dating that have the potential to influence men's sexual function. Women may also experience, for example, body image concerns around scarring or weight problems from treatment, early menopause, infertility, vaginal stenosis, and vaginal dryness, which make sex painful and can lead to sexual concerns or avoidance. Often, the sexual consequences of the physical and emotional side effects often go un-addressed or under-addressed by health care teams. For example, if a woman is experiencing pain and fatigue due to her treatment or diagnosis, she would most likely be assessed and managed by the oncology team, as pain and fatigue are now often viewed as essential parts of a full medical assessment (Given, 2008). However, the sexual consequences of having pain and fatigue or needing to take pain medication that consequently also reduces sexual performance typically go unaddressed.

Thoughts drive emotions and the voluntary and involuntary physiological responses in the sexual response cycle. Therefore, increased negative thoughts (e.g., "I will never be desired"), and distress about the diagnosis itself can influence sexual dysfunction and how the sexual self responds or reacts to the many physical, emotional, and psychological changes that

he/she will experience during and after treatment (Schover, 1998; Zebrack et al., 2004).

Cancer and its treatments can create significant disruption (regardless of age and disease site) to sexual response and satisfaction (Andersen, 1985,1990; Derogatis & Kourlesis, 1981; Schover, 1999; Wise, 1978). This chapter will continue to explore how a young adult might interpret the experiences and changes cancer can bring into his sexual self.

Young adults and sexuality.

According to Erikson (1968, 1998), young adults (aged 18 to 35 years old) are ready for intimacy with other people (and oneself) and try to find mutually satisfying relationships, primarily through marriage and friends. During this stage of life, many couples begin to start a family, though many are now waiting until their late thirties. Erikson's developmental theory claims that leading into young adulthood, adolescents begin to integrate many roles (child, sibling, student, athlete, and now cancer survivor) into a self-image under role models and peer pressure. If this phase is hindered or not met, it can lead to role confusion rather than a stronger sense of identity, and therefore interrupt their ability to form intimate relationships, since a sense of self needs to be present for healthy intimate relationships (sexual and non-sexual). During young adulthood, individuals seek one or more companions, along with mutually satisfying relationships in order to achieve intimacy on a deep level. Long term commitments are sought and if a young adult is not successful in participating in a mutually satisfying relationship he may find himself experiencing isolation rather than intimacy and this may influence his view of his sexual self.

Even in the "healthy population" there are major limitations in understanding the sexual and relationship issues that young adults aged 18 – 40 confront. The majority of

research on sexuality topics among adolescents and young adults have typically focused on sexually transmitted diseases, interventions to decrease negative outcomes, pregnancy and self-esteem. There are several studies and books that have discussed sexual difficulties in the older adult population (Alterowitz & Alterowitz, 2004; Leiblum, Rosen, Menza, & Marin, 2006; Foley, Kope & Sugrue 2002). Very few studies look at the general sexual health and sexual function of young adults, with most of the research on this population exploring the younger young adults (college age 18-25) with research taking place on college campuses.

A U.S. national probability study by Laumann, Paik, and Rosen (1999) reported on the prevalence of sexual dysfunction of men and women aged 18 -59. In this study, 32% of the 1,749 women reported a lack of sexual interest, 16% reported anxiety around sexual performance, 27% reported experiencing no sexual pleasure, 21% experienced pain with sexual play, 19% reported trouble with lubrication, and 26% reported an absence of orgasm (anorgasmia). In the male respondents (n = 1,410), 30% reported premature ejaculation, 14% experienced a lack of sexual interest, 7% reported anorgasmia, 19% reported anxiety about performance, 10% reported no sexual pleasure, and 7% reported difficulty in achieving or maintaining an erection. Overall, women showed an increased prevalence of sexual difficulties at 43% compared to men at 31%. The study concluded that various demographics contribute to sexual dysfunction for both men and women, including age and education. In addition, significant to this researcher's exploratory study, it was discovered that sexual dysfunction is more likely to occur (in both men and women) when poor physical and emotional health is present and is highly associated with negative experiences in sexual relationships and overall well-being (Laumann, Paik, & Rosen, 1999).

Although the study by Laumann and colleagues (1999) was one of the first to look at sexual problems in a large and diverse population, it certainly does not tell the whole story. One of the criticisms of this research was the use of the term sexual dysfunction, which implies “the sexual response system is malfunctioning” (Bancroft, Loftus, & Long, 2003, p. 213) and does not necessarily explore the psychological implications or influences. It was suggested that the term sexual problems or difficulties might have been more fitting to describe the data gathered as the questions asked did not assess for frequency or length of time the reported problem(s) has occurred. Conclusions cannot be made specifically from this about what young adults between the ages of 18 and 40 are experiencing when it comes to sexual dysfunction. Bancroft, Loftus, and Long (2003) questioned a large national probability sample of heterosexual women assessing the distress they experienced around sexuality. Researchers found that the best predictors of low sexual distress were markers of general emotional well-being and emotional connection with her partner during sexual activity. “Physical aspects of sexual response in women, including arousal, vaginal lubrication, and orgasm, were poor predictors” of sexual distress (Bancroft et al., 2003, p. 209). Although the sexual function reported for some, may be distressing, it also might be adaptable or flexible in their interpretation given their thoughts about their function, previous experiences, and/or coping skills (Bancroft et al., 2003). For example,

Low sexual interest may prove distressing for an individual but may also represent an adaptive response to overwhelming stress in one’s life...Manifestations [of sexual dysfunction] represent symptoms of a problematic state but does not necessarily imply a complete malfunction. (O’Sullivan & Majerovich, 2008, p. 110)

This information provides hope for the young adult cancer survivor who has a good emotional well-being and feels connected to his partner and therefore may have less sexual distress.

However, it is important to note that the case may also be that with sexual function high they have a more general sense of well-being.

Little is known about the positive or negative aspects of sexual function in this particular age group, especially in the younger young adults and those who are not coupled, as they may not have the history or experience to reflect upon. A recent study by Moin, Duvdevany, and Mazor (2009) researched sexual identity, body image and life satisfaction in women with and without physical disability. The results of this study showed women with physical disability had the same desires and sexual needs as women without disability. However, the women with physical disability demonstrated significantly lower body image, sexual self-esteem, sexual satisfaction, and life satisfaction. Significant to this research is that differences found were stronger among young adult women than among older adult women. “It was also found that sexual satisfaction was a major factor in explaining the variance in life satisfaction in both groups, and the relationships between sexual satisfaction and life satisfaction were bidirectional” (Moin et al., 2009, p. 83).

A study by O’Sullivan and Majerovich (2008) the authors found that individuals aged 17 to 21 had high levels of positive desire, pleasure, and satisfaction, but also varied life experiences of a range of sexual difficulties. When compared to older young adults (age 22 to 28) there was very little difference, suggesting that the “foundation for sexual functioning may be established early in the lives of young people” (O’Sullivan & Majerovich, 2008, p. 109). The authors also did in depth interviews with 30 of the 171 younger participants (ages

17 to 21) and found that the sexual difficulties they experienced appeared to significantly disrupt sexual and relationship functioning. Two interesting findings in the qualitative analysis of this study were that even when sexual interest was low (and often was reported low), sexual activity remained high in both males and females. Some reasons that were provided for this apparent discrepancy was that respondents felt pressure, or needed to perform for their partner and did not want to be perceived as unable or unwilling. Certainly other factors, such as stress, illness, diet, family and life changes, etc. could affect decreased desire as well, however, the authors did not further explore these areas.

The data gathered by O'Sullivan and Majerovich (2008) may have significant implications for the young adult cancer survivor. If the "foundation" for sexual functioning is established in older adolescence and young adulthood, then those diagnosed with cancer between these ages may get a "double whammy". The implications could be two fold. First, the survivor may be in the middle of establishing their sense of "normal" sexual functioning and cancer suddenly changes this normal, or secondly the "normal" might not had been established yet, so the sexual dysfunction caused by treatments is his normal and he knows no different. The latter may have less distressing results. One might also wonder if the young cancer survivor would be any different than those interviewed by O'Sullivan and Majerovich (2008) in the feelings of obligation to their partner to perform even if desire is low. Would a young adult survivor feel less of an obligation given their cancer experience and possible new views on life to perform sexually if they did not want to?

Young adulthood is typically a time of major changes, stress and exploration that can confound a young adult cancer survivor's developmental experience (Zebrack, 2008). Healthy

sexual development is based on “the delicate interplay of physical, psychological, and interpersonal factors. Young adults with chronic illness, including cancer, must tackle normative development issues and treatment-related challenges” (Olivo & Woolverton, 2001, p. 172). Cancer and its treatments can create challenges to the normative developmental process causing an interruption of identity development, the search for a world view, autonomy, future orientation and interpersonal functioning (Olivo & Woolverton, 2001; Robert, Turney, & Knowles, 1998; Stern & Zevon, 1993; Zebrack, 2008).

Younger young adults may still find the appearance of their adult body and sexual functioning fairly new, and a diagnosis of a disease could dramatically change their newly experienced awareness of their more developed sexual self. Olivo and Woolverton (2001) reported the comments of an 18 year old girl treated for leukemia, who stated to a social worker after suddenly breaking up with her boyfriend:

Now that I’m feeling better, he’s going to want to start having sex again. What he doesn’t know is that I’m not just bald, I’m completely hairless, and I mean completely! I look like a little girl! How could he want to be with me? (p. 175)

This young woman thought breaking up with her boyfriend was a better alternative than continuing the relationship and risking feeling more insecure and embarrassed about her changed body.

A young adult’s view of him/her self may be partly determined by his or her socially defined roles or positions (e.g., partner, star athlete, “smart kid”, student, father/mother, employee). When this role or position is lost or significantly changed because of a disease or a crisis, the resultant loss creates alienation from peers, which is an essential part of a young

adult's identity and development (Hughes, Sharrock, & Martin, 2003). This alienation might also have a negative result on the sexual self and sexual experiences the young adult participates in. A diagnosis of a chronic or terminal illness may deprive young adults of being understood by same-age peers who are physically capable, thereby preventing them from participating in normal and age-appropriate activities, including sexual experimentation, sexual activities and developing or deepening intimacy. All young adults will most likely experience some form of a challenge to their sexual identity and sexual choices as young adulthood is a "time of increased vulnerability and stress" (Zebrack, 2008, p. 1353). This increased vulnerability and stress could present young adults who face a chronic disease during these years with major milestone challenges above and beyond those faced by their peers (Evan, Cook, Kaufman, & Zeltzer, 2006; Lock, 1998; Zebrack, 2008).

The young adult with cancer.

Young adult survivors, in general, often have well-developed global self-concepts (Anholt et al., 1993), which of course may vary based upon their age at diagnosis. For example, a 32 year old may have a better developed global self-concept than a 23 year old. However, there have been reports that while they may feel accomplished and adequate in some areas, they seem to be less confident in their sexual self-concepts (Anholt et al., 1993; Evan, Kaufman, Cook, & Zeltzer, 2006; Fritz & Williams, 1988) and a diagnosis of cancer or other illness may create question or chaos in their sexual identity.

Young adults with cancer or who have had cancer may have problems with body-image perception and poorer sexual self-views and adjustments compared with healthy peers (Fritz et al., 1988; Jensen, 1992; Lock, 1998; Suris et al., 1996; Zebrack & Chesler, 2001).

There is very little literature on young adults specifically, however there are several studies that explore older adolescents and young adults of childhood cancer. In one study, adolescent survivors who were compared to healthy peers were found to differ significantly in the areas of body-image disturbances and sexual development (Madan-Swain et al., 1994). Pendley, Dahlquist, and Dreyer (1997), in exploring adolescent cancer survivor's body image and social adjustment, found that cancer survivors did not differ from their healthy peers in social anxiety, loneliness, or composite body image scores. However, those who were out from treatment longer did report lower self-worth, higher social anxiety, and a greater negative body image perception, but their attractiveness was not rated any lower than their peers by blind raters. The authors suggest that body image concerns and social anxiety may not develop until years after finishing treatment, which makes assessing, educating, identifying, and treating adolescent and young adult cancer survivors' various issues so critical, both during and long after treatment is completed. Stern (1993) also studied the perceived self-image and social support in adolescent and young adult survivors, and found that although the adolescents and young adults were relatively well adjusted, they displayed an overall less positive self-image in terms of their social and sexual self. How a young adult views his physical self does typically affect self-esteem or liking oneself (Magill & Hurlbut, 1986).

During the early young adult years, a significant part of self-esteem is derived from sexual identity and, therefore, a cancer diagnosis may challenge a positive sexual identity among young adults (Eccles et al., 1993). There is little written about the older developmental years of a young adult (e.g., 28 to 40) but in this researchers professional experience, the older young adult may be exploring how choosing to be single, or the

changing role of being single to a committed partnership and then having children, may influence the development of the sexual self. They may also be gaining more confidence, “peace” (as one young adult reported to this researcher), or comfort in their sexual identity and/or how they view themselves as a sexual partner and sexual person. Parents and peers may also influence the views and developmental changes in the sexual self of young adults throughout their young adulthood (Evan et al., 2006). In addition to the already challenging ongoing development of the sexual self as a young adult, the treatments for cancer and the late effects add a layer of confusion, delay, frustration, or may complicate sexual and intimate matters, causing the individual to further delay in growth of the sexual self. Young adults who are questioning their sexual orientation may find themselves putting that exploration on hold as they tend to their diagnosis and treatment. When treatment ends, they may discover that they are behind many of their peers who do not need to experiment as much, and feel confident in their sexual partner preference. This may lead to feelings of isolation and alienation. In addition, young adults who have a history of sexual abuse may already have sexual esteem and shame related to their sexual self and sexual history, which may be exacerbated by the further physical and emotional trauma that cancer can bring. They may also find themselves feeling as though they are reliving some of the trauma as they are poked, prodded, and ungowned in front of multiple health care professionals.

Unfortunately, isolation and alienation are commonly reported among adolescent and young adult patients and survivors as they often miss out on experiences that their peers are enjoying such as dating, leaving home and establishing independence, going to college, pursuing gainful employment, getting married, or having children (Roberts, Turney, &

Knowles, 1998; Zebrack, 2008). For example, a 25-year old female who, because of treatment has been put into premature ovarian failure, is anxious about the changes she observes in having “no desire” and wonders if she will ever “want sex” again as she listens to her roommates talk about their relationships.

Psychological and physical traumas during adolescence may “derail the development of one’s healthy adult sexuality. Increasingly, medical and mental health professionals are realizing that “treatment for childhood cancer may be one such trauma that proves to confound sexual development” (Olivo & Woolverton, 2001, p. 172). This may be true for young adults as well, as they are entering the already complex and challenging development phase of beginning to separate and develop independence from their parents, starting a career, finding a partner, and becoming a parent (Gould 1972; Levinson & Goodsen, 1985). As one 19 year old survivor of Non-Hodgkin’s lymphoma reported in research conducted by Olivo and Woolverton (2001):

My last chemo did not mark the end of my medical problems...After the treatment was over, my counts stayed suppressed for months, I was tired all the time and short of breath. Before my diagnosis, I was hoping to be a ballplayer. For a long time afterwards, sports were impossible for me to do. Now I still feel like I’m a little old man or something. And who knows what will go wrong in the future? (p. 174)

This young man was not only was struggling with the long term effects of the illness as many young adults do, but also saw himself as an “old man” which may lead to a decrease in self-esteem, sexual esteem, and a willingness to make himself vulnerable in dating situations.

Short term and long term side effects of treatment can affect a young adult's sexual self in both subtle and obvious ways.

Along with facing a mortality not many of their peers are faced with, new scars from surgery, physical limitations (like breathlessness), permanent hair loss, or other changes, will also need to be incorporated in to one's sense of self (Costanzo, Ryff, & Singer 2009; Evan et al., 2006). For the individual who may still be struggling with or perhaps is in crisis about who his 'self' is, the changes cancer can bring could have significant negative ramifications on his sense of self (Evan et al., 2006). For example, a young adult's self-esteem may be waning as she thinks "I can't have children the 'normal' way...I will never be normal and no one will ever want me." However, there is some evidence that an illness may also enhance a person's sense of self and competence, where the young adult may think "There are lots of people who are infertile...I am not any different from them; I will be able to be a parent of a child who really needs a home and will find a mate who wants to share this with me". The inability or ability to integrate this information positively into one's overall identity could influence the development of positive sexual and self-esteem (Erikson, 1998; Evan et al, 2006).

Results from a study by Costano, Ryff, and Singer (2009), examining psychosocial adjustment among cancer survivors, indicated that differences in mental health, mood, and psychological well being, along with pre- to post-diagnosis increases in mental health symptoms, were much higher and apparent in the younger cancer survivors. The authors speculate this could be due to the impact of cancer and its treatments on a young person's normal developmental stages and their inability to be autonomous or further develop intimate

relationships during treatment due to the treatment itself or the late effects. The decrease in social support may also contribute to this change in quality of life as their friends “don’t get it” or may be uncomfortable talking about their cancer history. Young adults may “also have greater demands in the areas of work or parenting and fewer coping resources, which make contending with cancer particularly stressful” (Costano et al., 2009, p. 147).

Cancer, its treatments, and the late effects associated with treatment (e.g., early menopause, infertility, and chronic fatigue), can affect sexual behaviors, attitudes, and identity in young adults (Bolte & Zebrack, 2008). “Altered perceptions of body image and self-esteem, changes in relationships, and other social life challenges can take a significant toll [on this population], for whom exploring and developing sexual and intimate relations is a norm” (Bolte & Zebrack, 2008, p. 116). Therefore, this study is assuming cancer and its treatments have a more negative influence on young adult cancer survivors and these effects on aspects of the sexual self go unaddressed and untreated, creating higher distress and lower quality of life (see Table 1 for summary of treatment effects).

Many cancer diagnoses have improved prognoses and therefore quality of life issues, such as sexuality, have become very important to address. Although mortality and outcomes have improved, late effects and quality of life issues are becoming more prevalent in the young adult population (Freyer & Kibrick-Lazear, 2006; Zebrack, Yi, Petersen, & Ganz, 2008; Zebrack, 2008). Therefore, cancer and its treatments can have long-term effects that need to be addressed (Zebrack, 2008), including issues related to a person’s sexual self.

Cancer and sexuality.

Common cancer treatments (e.g., chemotherapy, radiation, and surgery) impinge on a person's physiological, emotional, psychological, and sexual well being (Hughes, 2000; Pelusi, 2006; Schover, 1999) and also heighten areas of distress like pain, fatigue, depression, and anxiety (Zabora et al., 2001). Tan, Waldman, and Bostick (2002) warn to differentiate between primary and secondary causative factors for sexual problems after cancer. Primary factors, from the cancer or treatment, include physical or organic changes (e.g., hormone changes, anatomical changes, nausea, fatigue, etc.). Secondary issues are primarily psychosocial in nature, and both primary and secondary issues can individually or together have an effect on sexual response and fertility (Tan et al., 2002). Curtiss and Haylock (2006) note,

Cancer survivors often experience long term changes and obstacles, such as impaired immune response, vital organ dysfunction, hormone changes resulting in infertility, altered sexual function, cognitive changes, ongoing fatigue, depression, anxiety, family distress and economic challenges, to mention only a few. (p. 4)

Unfortunately, many treatments used to manage the distress related to depression, pain, or anxiety also create significant changes in the sexual response cycle complicating or exacerbating symptoms of sexual dysfunction (Ananth et al. 2003; Frumovitz et al., 2005; Hughes, 2000; Pelusi, 2006; Spagnola et al., 2003). In a study done by Carelle et al., (2002) exploring the perceptions of people who had received chemotherapy, changes in sexual desire were reported as one of the most interfering with greater quality of life. Sexual function and intimacy are also quality of life issues that are extremely prevalent to the “well” young adult

Table 1
A Brief Overview of the Possible Biological, Social, and Psychological Implications of a Cancer Diagnosis between the ages of 15 and 40

Biological and/or Physical	Surgical scarring, removal of limb, placement of ostomy	Late effects and ongoing side effects from treatment	Neurobiological changes	Second Primary Malignancies (getting cancer a second time due to the treatment they received)	Fertility problems	Developmental delays	Early Menopause: bone density loss, lack of period, hot flashes, cognitive/memory changes
Socially	Surgical removal of limb and/or Placement of an ostomy may require lifestyle changes and/or adaptations	Reestablishing themselves as survivor and finding their new identity	Role changes: moving home, leaving a job, leaving college	Peer support identified as one of the highest needs	Lack of continued health care	Financial concerns	Isolation due to treatment
Psychologically	Surgical scarring or removal of limbs could lead to negative thoughts and weaker sense of self	Could be a greater risk taker and place themselves in higher risk situations (unsafe sex, etc.)	May have a greater appreciation for life but sense of vulnerability	Tremendous loss and grief issues	Neurobiological changes that impact mood	Uncertainty about the future: leading to anxiety and or depression	Post-traumatic stress

population (Mosher, Chandra, & Jones, 2005), yet sexuality in the oncology setting is often ignored.

Research findings suggest that aspects of the sexual response cycle in survivors often decrease in intensity and frequency after treatment compared to pretreatment status (Syrjala et al., 2000), with the most common complaint by men and women being the decrease in libido. Problems with sexual function appear to be multifactorial in cancer survivors (Monga, 1995; Syrjala et al., 2000), influenced by the biophysical and psychological/emotional side effects and late effects of treatments in addition to how a person perceives all of these changes. Monga (2002) reports two variables that influence a cancer survivor's sexual function and view of his/her sexual self: dysfunction and disfigurement. Dysfunction can present itself in various physical and emotional ways (directly related to treatment effects) through effects like fatigue, menopausal symptoms, incontinence, unmanaged pain or pain medication, cognitive, and/or neurological changes. Disfigurement can present as surgical scarring, and visible physical changes such as drooling due to lack of motor/muscle control and weight gain/loss, and can promote poor body image (Monga, 2002). Dysfunction and disfigurement have the possibility of changing a young adult's perception of his self, feelings of loss around changes in his social and personal life and how he gains meaning of his world within the new limitations brought on by cancer and its treatments.

In a study by Tan et al. (2002), examining psychosocial issues, sexuality, and cancer, a woman who had a mastectomy, responded to the question "To what do you attribute the sexual problems you experienced?," stating:

Much of my problem was caused by anxiety and fear of rejection rather than actual physical effects. I imagined that sex would be the big hurdle to get over, and I discovered that it was not. I found that the more difficult hurdle was nudity. I feel it was the loss of my femininity and self image. When I slept at night and my hands touched my chest. I was startled when I was able to feel my ribs, feeling something hard instead of something soft. I found that I needed to wear my prosthesis when sleeping, not for my husband, but for myself. The grief I felt from losing my sexual pleasure has been more difficult than the cancer. (p. 311)

As seen in the statement above, for many cancer survivors, it is not the cancer itself that creates the sexual dysfunction, negative body image, or problems with intimacy, but rather the consequences of treatment and the changes the body experiences from cancer that have the ability to create a negative sexual self perception.

Late effects and sexuality.

Late effects can be defined as side effects of treatment that last months to years (some permanent) as a result of the cancer treatment and can include physical and mental problems as well as secondary cancers (NCI, 2009). It is not yet known just how long these late effects last and if they are pronounced or prevalent in a young adult population who are at their peak of sexual development and experimentation. The Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) report that empirical research is needed to explore all of the late effects and quality of life aspects of the cancer experience among adolescents and young adults in order to best inform interventions and trainings for health care providers (AYAO PRG, 2006).

The spectrum of late and long-term side effects can range from treatable (e.g., hyperthyroidism) to serious (e.g., fertility or secondary malignancies) to lethal (e.g., congestive cardiac failure) (Aziz, 2002). Unfortunately, it has been challenging to capture the young adult population in follow up treatment and/or gathering data on their long term experiences as they tend to be hard to follow and find after treatment (NCI, 2006; AYA0 PRG). Due to their high mobility, indifference to following up with their oncology team and being treated in community clinics, critical data on long and late effects is lacking on this population (AYA0 PRG, 2006; NCI, 2008; Zebrack, 2008).

Surgical removal of cancer and lymph nodes can have long term effects. Individuals who survive a cancer of the bone and/or soft tissue may experience what is known as a phantom feeling (a physical and psychological experience of pain, itching, etc. in the limb that was removed). Those who have lymph nodes removed are at risk for a number of physical changes that can adversely affect a person's sexual function and quality of life. For example, men who had lymph nodes removed near the kidney, bladder, testicles, or rectum may have a higher risk of infertility. Women who have lymph nodes removed under their arm have the risk of swelling and discomfort throughout their arm (lymphedema) and near their chest/breast, which could change sensation and a woman's view of herself. Lymphedema in the arm or chest may also create sexual behavior changes, as the woman and/or her partner may be afraid to put any weight on the affected arm.

Late effects of radiation and chemotherapy can include cardiovascular problems, and patients may experience inflammation of the heart muscle, congestive heart failure, and heart disease – all of which can impinge upon an individual's physical activity level, including sex.

Treatment to the chest may also cause injury to the lungs (this is especially true for those who have had a bone marrow transplant) including how the lung functions, thickening of the lungs, inflammation of the lungs, and difficulty with breathing. If one could imagine being a 28 year-old survivor who is trying to continue his social activities, to include playing on a club baseball team and keeping up with an aerobic gym class, it may be very difficult for him to keep up with his peers. This may significantly influence how he views himself and his quality of life, if he is not able to participate in the activities he enjoys with his peers. His lack of stamina may also directly and indirectly affect his sexual function, sexual esteem, and sexual affect.

Graft-versus-host disease (GVHD) occurs when a donated stem cell graft attacks the normal tissue of the person with cancer and can cause skin blisters, jaundice, rashes, and dry skin. Chronic GVHD occurs in 30% of patients who survive at least 100 days after allogeneic bone marrow transplant (BMT) and can attack the female genital tract. GVHD in the female genital track can cause a loss of depth in the vagina, scarring, and ulcers (NCI dictionary, n.d.). Palpable exams, sexual intercourse or many types of sexual play could be extremely painful to women who experiencing GVHD in the vaginal area. Long term skin sensitivity, dryness and changes in the skin's flexibility may also occur, and persons with GVHD have to take numerous precautions to prevent infection and maintain a healthy immune system. These side effects from GVHD not only have the potential of influencing how a young adult views herself, but also can affect sexual activities. Sexual activities may be limited due to skin tightness and sensitivity, vaginal pain, and often kissing may be challenging and less pleasurable due to the saliva glands in the mouth being affected.

Endocrine system (hormone) changes are also results of chemotherapy and radiation in both men and women. Chemotherapy can cause permanent damage to a young woman's ovaries, resulting in premature ovarian failure and menopause. This change in the hormones released from the ovaries can cause hot flashes, sexual dysfunction, osteoporosis (decreased bone density and increase risk of fracture), and premature menopause (which can cause infertility and exacerbate sexual dysfunction). Common presentations of sexual dysfunction after cancer include loss of sexual desire, difficulty achieving orgasm, pain with intercourse, sexual inactivity, and sexual dissatisfaction (Boehmer, Potter, & Bowen, 2009). Infertility for both men and women is a risk of chemotherapy treatments, however, younger survivors, especially men, seem to have a greater chance of recovering their fertility several years post-treatment.

Osteoporosis is one of the “most common late effect of cancer treatment and occurs more frequently in cancer survivors than in the general U.S. population” (Cancer.Net, 2009, ¶ 7). Those young adults who are at greatest risk are breast and prostate cancer survivors and childhood leukemia survivors as they are more commonly put into an early menopause. Early osteoporosis could influence activity levels and bone/joint comfort, which may directly impact not only physical activity and an individual's view of him/her self, but sexual activity as well.

Digestive problems are also common late effects in survivors. Some chemotherapy can be harmful to the liver and surgery or radiation to the pelvis can lead to scar tissue, chronic pain, and intestinal problems. This may include chronic diarrhea due to the body not being able to correctly absorb nutrients. Again, one could assume that the fear of bowel

incontinence or cramping may influence a young adult's sexual routines and feelings about himself. Sexual function can also be changed by treatments directly to the pelvis, such as treatments for colo-rectal cancers, which have demonstrated an increase in distress about sexual function and sexuality (Phipps, Braitman, Stites, & Leighton, 2008; Sprangers, Taal, Aaronson, & teVelde, 1995).

One of the most common complaints of all cancer survivors is long-term fatigue, which can be caused by anemia, pain, a slow thyroid gland, and/or depression (ACS, 2009; Cancer.Net, 2009). Cancer related fatigue (CRF) is “a persistent, subjective sense of tiredness with usual functioning” (National Comprehensive Cancer Network [NCCN], 2003, p. FT-1). As fatigue increases, activity levels decrease, and cardiovascular and respiratory functioning decrease, leading to the loss of physical function and chronic fatigue that may persist for months or even years after treatment (Evans, 2002; Wilmoth, Coleman, Smith, & Davis, 2004).

Wilmoth, Coleman, Smith, and Davis (2004) explored the possibility of a symptom cluster (three or more symptoms that are experienced concurrently) between fatigue, weight gain, and sexuality in women diagnosed with breast cancer. This study reported that each of these symptoms may be influencing one another and exacerbating each experienced symptom. Although fatigue is a common experience, it decreases activity level in survivors. Therefore, weight gain is common and adds to the already challenging body changes that treatments cause. Fatigue appears to have less of a long term effect on young adults who are active. However, for those who are not physically active during and after treatment, long term fatigue can impact quality of life (Blyer & Barr, 2007).

Many of these late effects can also be experienced as chronic pain and/or discomfort. When pain becomes chronic “it increases in complexity and leads to various psycho-social problems, including marital dissatisfaction and distress” (Monga, Tan, Ostermann, Monga, & Grabois, 1998, p. 317). Monga et al., (1998) examined sexual functioning and its relationship with psychological measures in persons with chronic pain. They discovered that among 70 participants in an outpatient pain clinic, there was a significant relationship between perceived ability to control pain and sexual functioning ($p < .01$ for Fantasy, Arousal Behavior, Orgasm, and Drive). To assess the impact of perceived ability to control pain and sexual functioning, they utilized the Derogatis Inventory of Sexual Functioning (DISF) and the Multidimensional Pain Inventory (MPI) (Monga et al., 1998). The DISF examines five domains of sexual functioning: sexual fantasy (cognition); sexual arousal; sexual behavior/experiences; orgasm; and sexual drive and relationship. Each domain has four to six items, which are preceded by a question and each domain’s ratings vary with the higher score indicating better functioning. The MPI (consisting of three sections) assesses a number of dimensions of the chronic pain experience, including pain intensity, emotional distress, cognitive and functional adaptation, and social support. The first section assesses the impact of pain on the patient’s life and has five scales: Pain Severity, Interference with Life, Life Control, Affective Distress, and Support. The second section evaluates the patient’s views of how he/she perceives others responding to his/her pain, and the third section evaluates how often the person participates in general activities (e.g., household chores). “Five of the dimensions in the MPI, namely, perceived interference by pain, control over life, involvement in household chores and outdoor activities, and general activity level were significantly correlated with several aspects

of sexual functioning” (Monga et al., 1998, p 325). Not only can pain influence the ability to have or enjoy sex, but it also influences quality of life factors, which also seem to have a direct correlation with sexual satisfaction. This study demonstrates how important it is to address all aspects of a person’s biopsychosocialsexualspiritual well being and the influence that basic daily needs/tasks can have on sexual function and perceived quality of life.

Body image.

Recent literature clearly identifies that cancer treatments can negatively influence adult sexual function and body image both immediately following diagnosis and years later (DeFrank, Mehta, Stein, & Baker, 2007; Nolte, Donnelly, Kelly, Conley, & Cobb, 2006). Body image is an individual’s cognitive and affective appraisal of one’s body (Reissing, Laliberte’, & Davis, 2005; Wade, Wilkinson, & Ben-Tovim, 2003) and health care providers identify this as an important health related quality of life issue. Much of the literature examines women with breast cancer or those who have had a surgical procedure that altered their physical appearance (e.g., head and neck cancers or a disease/procedure which required an ostomy pouch) (Fobair, Stewart, Chang, D’Onofrio, Banks, & Bloom, 2005; Price, 1992; Silva et al., 2008; Low et al., 2009). Some studies that have examined long-term breast cancer survivors have noted that body image disturbances may be seen in later years of survivorship despite positive emotional and physical functioning (Ganz et al., 1996; Hartl et al., 2003). Although certainly an important factor, surgical alteration is not the only long term effect on body image. Body image can influence sexual activity, adjustment, and function. Therefore, thoughts about one’s body image may have an overall affect on a positive or negative sexual self. Poorer body image can also limit natural sexual development (Tepper, 2005).

Ettinger and Heiney (1993) identified seven issues that were of concern to young adults, which included body image and self-concept along with sexuality. In a study by Lowenstein et al., (2009), questioning three hundred eighty-four women with pelvic organ prolapse (POP), sexual function was found to be related to a woman's self-perceived body image and degree of bother from POP. A multivariate linear regression model showed body mass index and changes in body image perception were the only independent factors associated with changes in the Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire (PISQ-12) (an instrument that can assess a woman's poor sexual function) scores following the POP intervention treatment. This study concluded that sexual function may be more related to a woman's perception of her body image than to actual physical (internal and external) changes from POP. Therefore, health care providers should not make assumptions about how a young adult's body image may be perceived based on the type of cancer or surgeries he/she had.

For survivors of hematopoietic stem cell transplantation (HSCT), there are several treatment and psychological side effects that adversely affect body image and sexual function. The majority of patients who undergo a HSCT are under the age of 50 and have reported positive and healthy sexual function prior to diagnosis and treatment (Yi & Syrjala, 2009). Appearance changes in loss of hair, skin rashes, dryness, scars, weight gain (often from the steroids they are required to take) often influence body image perceptions for both men and women (Humphreys et al., 2007; Mumma, Mashberg, & Lesko, 1992). Werlinger, King, Clark, Pera, and Wincze (1997) indicate that a more positive body image may be related to weight loss and significant increases in the frequency of sexual activity and sexual drive.

Unfortunately, many cancer survivors experience weight changes due to the treatments and young women are more likely to gain weight due to medically induced menopause. These survivors are also likely to experience a decrease in sexual desire. Given these changes post cancer, it would seem that survivors may have a more challenging time achieving a positive body image, (especially females) if indeed it is related to weight loss and sexual desire increase.

Sexual health concerns in the adult oncology population have been identified in several studies (Katz, 2005; Schover et al., 2002, 2003, 2004, 2005; Sundquist & Lee, 2002). “Cancer survivors are at risk for alterations in sexuality and sexual health as a result of changes in physiologic, psychological, and social dimensions of sexuality, and the interactions among these dimensions” (Tierney, 2008, p. 72). In a study by DeFrank, Mehta, Stein, and Baker (2007) examining body image and dissatisfaction in adult survivors with various diagnoses (whom were 2, 5, and 10 years beyond diagnosis), body image was not associated with age, length of time since diagnosis, or general treatment type for either gender. Rather, body image was associated with various medical and psychosocial factors, which differed for men and women (DeFrank et al., 2007). Beyond the obvious impact a limb removal might have on body image, skin changes, weight gain and acne from prednisone and chemotherapy, stretch marks from the weight gain, and scars left from the surgeries are all daily reminders of being “different”. These alterations can have either a direct or indirect influence on sexual functioning and perception of sexual self (Evan et al., 2006). For example, if a young adult has a poor self image due to the scarring surgery and radiation has left on her hip and thigh from a sarcoma, her poor view of herself and thoughts of being

disfigured may cause her to feel less desirable. With these negative thoughts and feelings present she may experience a lowered libido, even though the cancer treatments may not have caused continued sexual dysfunction.

In the study by DeFrank, Mehta, Stein, and Baker (2007), mean body image scores significantly differed according to the presence or absence of recurrence, multiple diagnoses, or metastatic disease and was significantly correlated with mental health, physical health, and sexual dysfunction. For women, a more negative body image was associated with poorer mental health and sexual functioning scores. For men, the association between mental health scores and body image was also significant, where mental health scores were associated with poorer body image. Mental health as explored in this study included reports of bodily pain, lack of vitality, emotional problems limiting the fulfillment of one's roles, and ability to function in social settings. The researchers also reported that time from diagnosis did not influence a negative or positive body image, but rather that body image stays stable from two years post diagnosis on. This finding reinforces the importance of identifying poor body image in survivors both at diagnosis and in all follow up appointments as "time" does not necessarily improve one's thoughts and impressions of one's self.

Alterations in body image, sexual perception, function, and/or health can negatively affect the quality of life of cancer survivors (Ferrell & Dow, 1997; Hughes, 2000; Katz, 2005; McKee & Schover, 2001). The alterations occur when there is discrepancy between how the individual saw himself prior to a cancer diagnosis and the changes that have occurred due to cancer and its treatments, which now influence his view of himself (Hopwood, 1993; Wapnir, 1999). A positive body image is an essential element of a positive sexual self view in

adolescents and young adults (Tepper, 2005). Even healthy adolescents and young adults are concerned with their appearance and focus on self-improvement, but the physical changes that cancer and its treatment bring can have a highly negative impact on their self-image (Walker, Wells, Heiney, Hymovich, & Weekes, 1993).

Neurobiology and sexual function after cancer.

Just as thoughts and interpretation of events affect sexual function, neurobiology is also a critical component of sexual function and important to the explanatory theory of this paper. The brain is a major organ whose anatomy and function is regulated by testosterone, estrogen, progesterone, and other hormones associated with the reproductive system. Many different organs and systems are involved in coordinating sexual response including the brain, the spinal cord, blood vessels, the reproductive organs, and various hormones such as testosterone and estrogen. Interference with any one of these factors can result in sexual dysfunction (Crone & Wise, 2004; Plaut, Graziottin, & Heaton, 2004). When examining desire, arousal, and orgasm, there is a complex interaction of the endocrine, nervous, and vascular systems. The biological basis of each of these phases—desire, arousal, and orgasm—is important for health care providers to understand in order to correlate organic issues with functional problems (Crone & Wise, 2004).

Hormone levels play a critical role in sexual activity. In males, testosterone levels remain generally above the threshold required for sexual interest and activity, however testosterone levels can be impacted by affected by treatments and treatments directly to the pituitary or adrenal glands. Testosterone deficiency can have an adverse affect on sexual function in women as well, and recent research has shown that women who are post cancer

treatment have reported some benefit with the testosterone dermal patch improving their sexual desire and performance (Shifren et al., 2000). (It is important to note there are many women, who because of their estrogen positive cancers, such as certain breast cancers and ovarian cancers, cannot use hormone replacement to assist). Women with estrogen deficiency can experience a decrease in genital lubrication caused by the thinning of the vaginal wall, which can create distress and discomfort during sexual encounters (McKee & Schover, 2001). Decrease in estrogen levels occurs for most female cancer survivors both during and after treatment since the chemotherapy slows the function of the ovaries and may either induce a temporary or permanent medical menopausal state (Boehmer, Potter, & Bowen, 2009; Henson, 2002; Meston & Frohlich, 2000). Although removal of the ovaries does affect desire for women, the removal of the adrenal glands in women with cancer has been found to have an even more significant impact on desire and sexual function (Meston & Frohlich, 2000). The hormone dehydroepiandrosterone (DHEA) is produced by the adrenal glands. Levels of DHEA decline naturally with age and fall rapidly in cases of adrenal failure. Both elderly people and those with adrenal insufficiency report a drop in libido (Derzko, Elliott, & Lam 2007).

A net decline in testosterone levels occurs following natural menopause.... The symptoms of low androgen in women are reported to be similar to those in men: a decrease in libido, energy, or sense of wellbeing, and decreased lubrication and arousability even in the presence of estrogens. (Derzko, Elliott, Lam, 2007, S30)

Other hormonal influences on sexual function include oxytocin, cortisol, pheromones, and prolactin, all are naturally occurring in the body. There is some evidence showing that

oxytocin levels increase during sexual arousal and orgasm in both men and women (Bartlik et al., 1999), however most studies have been done on animals. Studies of men and women with elevated levels of prolactin report decreased sexual interest, arousal, orgasm as well as mood disturbances such as anxiety and depression (Schagen et al., 1998). Erectile dysfunction has been described in men with both abnormally low and abnormally high prolactin levels, as prolactin counters the effects of testosterone. Additionally, women with high prolactin also may experience infertility and decreased sexual activity. Prolactin is released by the pituitary gland, so if there has been any damage to the pituitary gland in treatment for the cancer, the person may have permanent sexual function problems (Smith & Gillam, 2005). For childhood survivors who have had a brain tumor or treatment to the brain that impacted the function of the pituitary gland, they may be sexually underdeveloped (meaning smaller size sex organs and breast size). Prolactin also interferes with dopamine levels which then may help explain the exacerbated effect that SSRIs have on a patient's sexual function (Crone & Wise, 2004).

Ovarian androgen production commonly ceases with chemotherapy, as well as with radiation to the gonadal areas or to the pituitary gland. Estrogen-receptive drugs such as Tamoxifen or other aromatase inhibitors, typically prescribed to breast cancer survivors with estrogen sensitive cancer, also influence hormonal release from the ovaries (Henson, 2002). The ceasing of androgen production can induce premature ovarian failure (POF) in females, and for males can stunt or stop the growth of testes, both of which can be devastating to the individual. "Androgen loss undermines the neurobiology of sexual drive and central/subjective sexual arousal, given androgen's biological "initiating" role in the seeking appetitive pathway in the brain" (Graziottin & Basson, 2004, p. 771). Androgen loss certainly

can change the biological function of sex, but the loss of desire, arousal, and orgasm may also influence the psychological and emotional responses to the change in sexual function. Some women/men may be able to adjust without distress to the change in their sexual desire and function, and others may experience increased distress, depression or anxiety, which then indirectly influences sexual function. When depression is high, sexual desire is low and, therefore, sexual response is challenged (Graziottin & Basson, 2004). One might also be able to argue that when sexual desire is low, depression is high and therefore, sexual response is challenged. Although it may be challenging to control for and carry out, research has yet to explore whether low sexual desire might lead to more negative psychological outcomes that then creates greater distress and lower sexual function.

Sexual function is not only affected by the treatments for cancer that influence hormones, fatigue, cognitive function and mental health, but it is also affected by the medications given to counteract late effects or manage mental health problems. There can be problems due to certain drugs such as antidepressants (selective serotonin reuptake inhibitor [SSRI]), antihypertensives, anticholinergics (used for example to treat urge incontinence, bowel problems, and breathing problems is a substance that blocks the neurotransmitter acetylcholine in the central and the peripheral nervous system), corticosteroids, hormone treatments such as Tamoxifen or Arimidex, and others. All of these medications are commonly prescribed to cancer survivors to manage the side effects of treatment as well as to manage the symptoms of depression (Gatz, 2002). However, recent studies have shown that the use of Bupropion (Wellbutrin) at 150 mg has significantly improved desire, arousal, and the ability to reach orgasm in female cancer survivors (Derzko, Elliott, & Lam, 2007; Mathias

et al., 2006). This new finding may help in counteracting some of the neurobiological side effects of cancer treatments and depression on sexual function. Unfortunately, for young women who have to take Tamoxifen, it is now not recommended to take Wellbutrin due to recent studies showing an interaction of the two drugs, decreasing the effectiveness of Tamoxifen (Henry, Stearns, Flockart, Hayes, & Riba, 2008).

Knowing what happens in the brain during sexual arousal and orgasm can help illuminate why so many young men and women have problems during sexual activity after a cancer diagnosis. As previously identified, there are various factors for both men and women that can cause sexual dysfunction such as depression, everyday stress, and managing multiple late effects from a cancer diagnosis. Having a greater understanding of the sexual differences in both men and women can help differentiate male and female sexual problems and allow the social worker to discuss gender and treatment-specific problems. Young adult cancer survivors may need to get creative in their sexual routines. For example, taking a phosphodiesterase inhibitor (Viagra, Levitra, or Cialis) for erectile dysfunction, or utilizing a clitoral sensitizing agent (a warming cream or oil used to help increase clitoral engorgement) or the EROS clitoral therapy (a device that helps increase blood flow to the clitoris and external genitalia) to enhance sexual response may be beneficial (Derzko, Elliott, & Lam, 2007; Schroder et al., 2005).

Quality of life.

Quality of life (QOL) is a term commonly used in research on cancer survivors' overall well-being and enjoyment of life. Many of the studies that evaluate quality of life in cancer survivors study "aspects of an individual's sense of well-being and ability to carry out

various activities” (NCI, 2009) in four common domains: physical, psychological, social, and spiritual well-being (Ferrell, 1996). Changes in one aspect of quality of life (e.g., pain) can influence perceptions in other domains (e.g., sexual function) and are best evaluated when defined from the patient’s perspective (Ferrell & Hassey, 1997).

Research on quality of life, or aspects of quality of life, has grown substantially over the past 30 years. In 1990, the NCI began using newly developed QOL measures to evaluate the impact of various treatments, identify side effects, and predict responses to future treatments (Cella & Tulsky, 1993). Quality of life instruments typically identify and assess concerns related to emotional and psychological distress, physical function, sexuality, spirituality, relationships, attitude toward the future (assessing hope, distress, depression, etc.), and current work/school performance. Research with 120 patients on quality of life at end of life identified five major areas of concern by the patient: existential concerns, spiritual concerns, family concerns, physical symptoms, and emotional concerns (Greisinger, Lorimor, Aday, Winn, & Baile, 1997).

Ferrell et al., (1995) developed and tested the Quality of Life for Cancer Survivors instrument, which was one of the first of its kind, examining the various aspects of health related quality of life, such as fertility issues, distress, and fear of recurrence. The data was collected from persons both in treatment and those who had completed treatment. Patients reported the areas that most affected their quality of life were perception of control, uncertainty, pain and aches, their future appearance, satisfaction, and fatigue. Individuals who were five or more years out from treatment and those who had a family income of over \$40,000 had higher QOL scores, where those who were living alone reported overall lower

quality of life. The top predictor of poor quality of life was the perception of control and it accounted for 46% of the variance. Second in line in predicting QOL was the identified experience of ongoing aches and pains and fatigue. Clearly, this research has implications for young adult survivors as well. Given that young adults are typically at their physical prime, working, raising families and/or going to school, in addition to working towards trying to gain more control and autonomy in their life, perceived quality of life could be low. In addition, if a young adult's intimate and sexual relationships are influenced by the physical and emotional limitations reported above, it is possible that perceived quality of life could be lower.

Quality of life is a subjective measure and certainly can vary based on a person's perceived experience, and internal and external resources, as well as their diagnosis, treatment protocol, prognosis, etc. However, all persons diagnosed with cancer will experience a change in aspects of their quality of life (Rowland, 1990). "The survivorship literature supports [Rowland's] theoretical assertion that, regardless of the type of cancer, all people diagnosed with cancer experience altered relationships to some extent, dependence-independence issues, achievement disruptions, impact on body and sexual image and integrity, and existential issues" (Zebrack, Yi, Petersen, & Ganz, 2007, p. 891). Limited research exists on the quality of life of young adult cancer survivors, diagnosed as young adults (Roberts et al., 1997; Zebrack et al., 2006; Zeltzer, 2006) and most of the literature reported in this dissertation has been drawn from research focused on young adults who are survivors of childhood cancer.

Quality of life and sexuality.

Zebrack and Chesler (2001) studied cancer-specific and general health worries of 303 childhood cancer survivors (individuals that had been off treatment for any length of time and

were 14- 29 years old) and concluded that males reported less cancer-specific and general health worries than females and older survivors reported increased worry about cancer-specific issues than younger survivors. Another study by Mackie, Hill, Kondryn, and McNally (2000) evaluated 102 childhood survivors of acute lymphoblastic leukemia (ALL) and Wilms tumor, aged 19 – 30, and compared them to 102 healthy non-related peers evaluating psychiatric disorders, intellectual ability, and interpersonal and social-role performance. There was no difference in the rates of psychiatric disorders, but survivors did report significantly poorer functioning in partnered sexual relationships, friendships, non-specific social contacts, and day-to-day coping than their comparison group.

Examining quality of life aspects in persons post-transplant, Baker et al. (1994) reported overall above average satisfaction with life in most domains but found lower satisfaction in body appearance, physical strength, and the inability to attain sexual satisfaction. Curbow et al., (1993) explored loss and recovery themes in 135 long-term survivors and identified that interruption in life plans, inability to have children, difficulties with sexual functioning, physical disability, and psychological loss were themes most often reported.

Gender differences (Prieto et al., 1996), body image (Fobair et al., 2005; Ganz et al., 1998; Sutherland et al., 1997), those diagnosed at a younger age, and report single marital status (Somerfield et al., 1996) have all been reported to affect quality of life issues in persons diagnosed with cancer. Despite the various treatments and sometimes long term consequences cancer and its treatments can have on survivors, over 50% will eventually adapt successfully to their illness (Spencer, Carver, Price, 1998). It is not clear if this successful adaptation

includes adapting to changes in sexual health or if a person finds new ways to mostly adapt to the new changes, but still feels loss or distress about previous abilities. Block (1997) identified that the predictors for positive adaptation included one's ability to remain actively involved with daily life, to maintain role stability (as student, parent, etc), and to cope with emotions related to the illness. However, even those who are "well-adjusted" have reported poorer functioning than their peers in areas such as sexual relationships (Mackie, Kondryn, & McNally, 2000).

Cancer survivors experience a vast array of negative thoughts and emotions such as the fear of dying, loss of self-efficacy, impaired self-esteem, fear of rejection or abandonment, weight, sleep and appetite disturbances, role changes, etc. which can impact one's interest or desire for sex and enjoyment of intimate relationships (Anllo, 2000; Block, 1997; Razavi & Stiefel, 1994). Alterations in a person's sexual self perception negatively affects the quality of life of a cancer survivor (Ferrell & Dow 1997; Hughes, 2000; Katz, 2005; McKee & Schover, 2001; Prieto et al., 1996). Clearly, sexuality and sexual health are key aspects of a person's perceived quality of life. However, research is lacking in the exploration of whether addressing an individual's sexuality and sexual health concerns enhances his/her quality of life.

Psychological distress.

"Distress is an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with people's ability to cope" (NCCN, 2007, p. DIZ-2). Therefore, psychological distress may be viewed as an aversive reaction to perceived internal and/or external stressors, which lead to actions aimed at addressing, adjusting to, or ignoring

stressors (Derogatis & Melisaratos, 1983; Zabora et al., 2001). Although research shows that cancer survivors are likely to experience increased psychological distress following a cancer diagnosis, distress is not always recognized, addressed, or followed for change by health care professionals (Borval, Maunsell, Brisson, & Masse, 1998; Hoffman & Recklitis, 2009; Zabora et al., 2001; Zebrack et al., 2007). The psychosocial and psychological distress needs of the adolescent and young adult group are specific and differ from those of either children or adults (Ellis, 1991; Mulhall et al., 2004; Ritchie, 2001; Smith, 2004; Society for Adolescent Medicine, 1996). “Off-time”, or non-normative, life events occurring outside the typical age range, such as a cancer diagnosis or a change in expected sexual function in young adult years when typically occurring in older adults, are more likely to be distressing or traumatic to a young adult (Baltes, 1979; Costanzo et al., 2009; Erickson, 1998; Neugarten & Hagestad, 1976).

Although some studies have shown cancer survivors to experience positive effects from their diagnosis (Belizzi & Blank, 2006; Park & Helgeson, 2006), there are several reasons why a survivor might experience increased psychological distress. An estimated 29.6% to 43.4% will experience elevated levels of distress (Zabora et al., 2001). Many individuals will have to make physical and functional adaptations due to the long-term impact of treatments, including secondary cancers. Lower physical health and lower functioning has been reported among cancer survivors. Factors related to chronic physical conditions (e.g., cardiac problems, infertility, physical disabilities, etc) and social functioning (e.g., employment issues, insurance issues, and changes in social life) all have been identified in survivors to increase overall psychological distress (Kornblith, 1998; Zabora et al., 2001;

Zebrack et al, 2007). “As a result of their cancer experience, many cancer survivors develop a fear of recurrence, health worries, a heightened sense of vulnerability, sense of loss for what might have been and alterations in social support” (Hoffman & Recklitis, 2009, p. 1274).

The presence of heightened psychological distress has been shown to increase a number of negative quality of life and health outcomes including poorer quality of life across multiple domains (Kirch & Passik, 2002; Skarstein, Aass, Skoglund, & Dahl, 2000). In a longitudinal observational study of 151 women with early-stage breast cancer, Jim et al., (2007) found that physical symptoms and side effects experienced during treatment were predictive of posttreatment cancer-related distress. Recently, the Institute of Medicine (IOM) (2007) reinforced in their annual reports the importance of identifying and recognizing the prevalence of distress in persons diagnosed with or with a history of cancer. This report comes at a time when it has been recognized that some cancer survivors experience significant long term physical and psychological problems.

Persons surviving cancer for at least five years are more likely to show signs of psychological distress than their peers (Hoffman & Recklitis, 2009). Hoffman and Recklitis (2009) evaluated psychological distress in those persons diagnosed with cancer as an adult five years or more post-diagnosis ($N= 4,636$) as compared to their peers (persons with no cancer history within same age brackets) ($N= 122,220$). They reported that high psychological distress was identified in more than 40% of the survivors that participated in the study in comparison to their matched peers. Data showed the 30 day prevalence of serious psychological distress (SPD) levels were significantly different between the two groups ($p < .001$), with 5.6% of the survivors showing SPD compared to their peers at 3.0%. After

adjusting for several factors (including age and gender) the cancer survivors still showed a significantly higher distress. Sex, age, and years since diagnosis were not associated with experiencing SPD among survivors. However, 1 in 18 adults diagnosed with adult onset cancer, five or more years from diagnosis, and residing in the United States reported serious psychological distress.

Factors that appeared to predict serious psychological distress in the long term cancer survivors included the following, reported as adjusted odds ratios (Hoffman & Recklitis, 2009):

- Age less than 45: 5.6 (95% CI 3.3 to 9.5) relative to those 65 and older
- No spouse or live-in partner: 1.7 (95% CI 1.2 to 2.4) relative to those married or living with partner
- Less than high school education: 2.1 (95% CI 1.5 to 3.0) relative to at least high school education
- Uninsured: 2.4 (95% CI 1.6 to 3.7) relative to insured
- At least two comorbid conditions: 3.5 (95% CI 2.2 to 5.6) relative to no comorbidities.
 - More than 25% of those aged younger than 45 with a comorbid condition reported having SPD
- Current or former smoker: 1.7 (95% CI 1.2 to 2.5) relative to never having smoked
- Difficulty with activities of daily living: 3.6 (95% CI 2.5 to 5.3) relative to no difficulty

This data is important to understanding and interpreting young adult cancer survivors' experience of distress, as many of the above factors (uninsured, comorbid conditions or

secondary cancers, no spouse or live-in partner, and aged under 45) may be common factors in their lives (Hudson et al., 2003; Zebrack et al., 2004; Zebrack et al., 2007). Sexual and relationship concerns have been reported to increase psychological distress in cancer survivors (Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Schover, 1994; Schag, Ganz, Ponninsky, Fred, Hirji, & Petersen, 1993). It was this researchers intention to explore whether there is a relationship or interaction between a negative sexual self and higher psychological distress and poorer quality of life.

The Relationship of Sexual Self, Psychological Distress, and Quality of Life

Critique of the Research.

Change in sexual function is one identified late effect of cancer treatments in adults. Currently, there are few studies that examine the young adult cancer survivor population and none that specifically look at the impact cancer and its treatments have on their sexuality. Although there has been a heightened awareness of fertility issues in young adults, the literature is still lacking in examination of other sexual health issues (Oeffinger & Hudson, 2004; Oeffinger & Robinson, 2007). There is also a large gap in the literature looking specifically at young adults and not grouping the young adults with adolescents, who often present with different developmental needs and issues. Sexual function and intimacy are quality of life issues that are extremely prevalent and under-addressed in the “well” young adult population (Mosher, Chandra, & Jones, 2005). Therefore, it seems probable that if cancer and its treatments influence sexual function and intimate relationships, the influence on quality of life of young adult survivors may be significant. Further neglected in the research is whether young adults experience similar late effects reported by their adult counterparts,

such as, but not limited to, lowered libido, infertility, erectile dysfunction (ED), or vaginal dryness.

Research studies examining the impact of cancer on sexuality in adult populations have demonstrated several limitations in their applicability to the young adult survivor population. These limitations are the lack of inclusion of various cancer diagnoses, the requirements for participation, the age of participants, the location of the research studies, and other design limitations such as the use of longitudinal retrospective design.

One of the limitations of research on sexuality and cancer is that it tends to explore only individuals who have been diagnosed with a cancer that directly affects a sex organ, like breast or testicular cancer, excluding many other diagnoses (Andersen, 1996; Andersen, Cyranowski, & Espindle, 1999; Henson, 2002). Young adult cancer survivors make up a small percentage of these diagnoses and, therefore, it would be challenging to draw comparisons and conclusions about the impact of treatments on sexuality. Other limitations of studies regarding sexual health and sexual function are the inclusion criteria itself. Often, English must be the participants' primarily language, along with having an absence of recurrent cancer and/or non-metastatic disease (Hendren et al., 2005; Nesbakken et al., 2000). Excluding individuals with advanced disease in the research on sexuality not only furthers the myth that persons with advanced disease are asexual, but also greatly limits the literature, as more people are living longer with cancer and/or getting secondary cancers.

Of the literature that explores sexual function, sexual distress, etc., few have used comparison groups and even fewer have explored the long term interactions with sexuality. This gap in the literature makes it challenging to draw conclusions on the long term follow up

care needs of patients. The lack of research on both survivors and healthy peers makes it difficult to establish whether there is a correlation or relationship(s) between a cancer diagnosis and changes in, for example, sexual function. The probability that the individual has learned to adjust and cope with new limitations or does not know what is “normal” sexual function would be a limitation to these studies (Freyer & Kibrick-Lazear, 2003; Oeffinger, 2003). For example, it is possible that a young woman who had not experienced much sexual activity prior to her cancer diagnosis is not able to identify changes in vaginal dryness after cancer treatments, and may have found ways to compensate without experiencing any distress. Where possible, future studies should consider measuring sexual function or sexual self-perceptions pre-treatment and post-treatment, using valid instruments and/or qualitative means so that the current problem of noncomparability across studies is improved (Hendren et al., 2005). Reports have identified that adult patients welcome their oncology staff to inquire about their sexuality and are willing to discuss sexual concerns (Canada et al., 2005; Cull, 1992; Schover, 1999). However, these results may not be generalizable to the young adult survivor population, as young adults between the ages of 18 – 39 are in a different developmental state both emotionally and sexually.

Many of the studies on childhood and young adult survivorship issues are sponsored by a single institution, some limited consortia, and, occasionally, cooperative clinical trials between selected cancer centers limiting the sample demographics (Kyngas et al., 2001; Puuko et al., 1997; Robinson, 2001). Moreover, most research in sexual health and cancer has been within large cancer centers, primarily Comprehensive Cancer Institutes, which are located in major cities around the United States. Although many of these studies have used

random sampling, there may be a bias in the persons who are being treated in these types of institutions along with limited sample size. Furthermore, less than 15% of all cancer patients are treated in these types of centers. The remainder received care in a variety of community-based hospitals, clinics, and group practices (Adler & Anne, 2008). For instance, representations of rural populations are probably very minimal and diverse ethnicity is clearly underrepresented in the literature outside of breast cancer and sexuality (Hendren et al., 2005; Puukko et al., 1997; Zebrack et al., 2004). The research may not be a clear representation of the group being studied as participants would need to have a telephone, transportation, and an address to participate in post treatment follow-up studies.

Locating a large number of young adult cancer survivors could pose a problem simply because of who makes up the population (e.g., individuals who are frequently moving and changing names). An additional challenge to capturing a representative sample of survivors is that as adolescent survivors become young adults they do not always follow up in survivorship clinics or with their pediatric oncologists. This may also occur for the young adult diagnosed with a pediatric cancer as they find themselves stuck between the pediatric and adult oncology worlds and unaware of survivorship clinics. In addition, most often these patients are followed by their primary physicians or mainstreamed into adult medicine, which poses another threat. While more detailed intervention studies of sexual function and chronic illness for providers have taken place in Europe and Australia, their location decreases the results' generalizability to the United States as cultural discussions about sexual health are more open and mainstreamed in these countries (McGinnis, 2000).

In long term follow-up studies, an important consideration is that the data presented from the Children's Cancer Group (CCG), represent only the patients enrolled in a treatment study, not necessarily all patients registered at CCG. Therefore, young adults who registered for a treatment study or clinical trial, but either were not eligible or did not complete the study or clinical trial are not followed by the cooperative clinical trials groups, and therefore data about these individuals is missing (Robinson, 2001).

The qualitative research studies on young adult cancer survivors appear to mostly utilize convenience samples and have explored psychosocial issues and needs (although more literature seems to be arising that includes sexual health questions within psychosocial assessments) (Elad et al., 2003; Kyngas et al., 2005; Roberts et al., 1997; Zebrack et al., 2004). Convenience sampling may be utilized with this population due to the difficulty in locating a large enough sample of young adult cancer survivors. Currently, there are a handful of cancer survivor camps and support programs, such as Camp-Mak-A-Dream and the Lance Armstrong Foundation, targeted toward the young adult population that are ideal situations for researchers to gain a captive and usually willing audience.

The most frequently used qualitative research methods were narrative reporting and focus groups. One study in particular did not utilize a structured questionnaire/interview, but rather based a few general questions on the Lazarus and Folkman's model of coping. One question utilized in this study ("What are the factors that hindered you from coping with everyday life?") appears to be a negatively framed question, assuming that a survivor would not be able to cope with everyday life. This question also utilized a phrase [factors that hindered] that might not be clearly understood by all young adults (Kyngas et al., 2001). A

more positively or neutral framed question might be, “Some young adults have reported experiencing challenges in managing the day to day stuff of life. What things did you do to manage any challenges you experienced?” This question normalizes the experience and continues to utilize an open-ended format while focusing on the strengths of the individual. In addition, missing from much of the young adult survivorship literature (and other cancer population literature) are studies that describe what variables contribute to sexual dysfunction, how perceptions of the sexual self change during or after treatment, the impact of sexual changes on the biopsychosocialsexualspiritual recovery of the patient, along with a comparison to other groups of survivors or a within group comparison of different diagnoses (Holmes, 2003; Zebrack et al., 2009).

In conclusion, there is clearly literature that supports the experience of quality of life, distress and changes in a cancer survivor’s sexual self (sexual function and behavior, sexual esteem, sexual feelings/affect). However, there are clear limitations in the research examining the young adult survivor population. Further research that utilizes both qualitative and quantitative methods is needed to explore not only the experience of cancer on their sexuality, but the direct physiological and psychosocial impact cancer had on sexual functioning. Future research must be designed in such a way as to truly capture the experience and expression of the late effects cancer and its treatments may have on young adults’ sexuality and perception of their sexual selves.

Theoretical Framework: Cognitive Theory and the Cognitive Integrative Perspective

Cognitive theory and the self: Knowledge about one's self.

Cognitive theory claims that an individual is an “information-processing organism, one who takes in data (from both outside sources and inside reading) and generates appraisals” (Schuyler, 1991, p. 34). Schemata are memory structures of conceptually related elements that guide the processing of information. Self-schemata are then the cognitive generalizations we create about the self, derived from repeated experiences, categorizations, and evaluations of behavior from oneself and others (Berlin, 1996). The data or information gathered are stored in two types of memories, episodic and semantic, in order to be drawn from and make sense of events. Episodic memory (introspective knowledge about one's thoughts and perspectives) and semantic memory (general knowledge about concepts, attributes, and language) influence various mental representations about the self and contribute to the knowledge that is drawn from to “make sense out of what they encounter, to identify options for responding, and to experiment with efforts to manifest or do what is desired and to avoid or guard against what is undesirable” (Nurius, 1994, p. 224). As life experiences continue to occur, these memories are stored as schemata in order to organize all of the events and memory patterns to help us know “what goes with what” (Berlin, 1994, p. 6) and guide our interpretation of events. Functions of self schemata are to organize incoming information into an integrated knowledge structure, to help with the retrieval of behavioral instances, to resist inconsistent information and to provide plans for future behaviors or push toward future goals (Markus, 1977). These schemata guide the development of various selves and the information we select about ourselves in various situations (Markus & Nurius, 1986).

For example a young man who is going to a party where he will know few people may retrieve the schema of 'people person' with the thoughts "I'm friendly and people generally like me" and therefore, he is able to feel calm and relaxed, and perceives the experience as positive.

Repeated similar experiences teach us what to expect, what to do, and how to understand our needs and resources (Berlin, 1996). Individuals impose different interpretive patterns, schemata, on similar events and then construct our own experience of that event. Negative thoughts about the self seem to be the most prevalent thoughts when a person is depressed or experiencing a lower self-evaluation. These negative thoughts appear to generalize all other thoughts about the self and become the lens through which the individual looks. On the contrary, when a person experiences thoughts of competence, these thoughts trigger both positive feelings and positive behaviors that express more confidence (Markus, 1977).

Individuals adapt by searching and constructing meanings that will enhance their sense of security and continuity and serve their goals. The meanings people construct are a function of their experience-based cognitive systems for understanding and the nature of the information available to them. (Berlin, 1996, p. 326)

Cognitive theorists support the idea that individuals contain many selves and access them when making sense of a particular thought, situation, or event (Berlin, 2003; Markus & Nurius, 1986; Nobre & Gouveia, 2000). As self experiences accumulate and memories mount up, Berlin (2002) states:

Our overall sense of self...becomes more complex...(and) whatever the array of self-relevant sensations, definitions, images, feelings, and actions are active at the moment makes up what is variously referred to as the “working self-concept”...and is the self that is in charge at the moment. (p. 98)

These “working self concepts” or “possible selves” are subsets of self-schemata that represent the hopes and desires we strive for, including our sexual desires (Berlin, 2002).

Markus and Nurius (1986) suggest that we may in fact have several ideal or possible selves. We have a range of ideal selves, some of which we access regularly, such as a working person’s professional self. Possible selves are projected images of who we could become and sometimes these will be good, such as a desired parent self, and other times they may not be. For example, Markus and Nurius (1986) cite the case of a man in a troubled marriage who might see his ideal self as a divorcee, but at the same time he might be fearful of life without his spouse. It is argued that possible selves can be motivating factors in determining how we behave. Thus, in the above example, the man may be motivated to try and save his marriage by the image of his divorced self, as he may imagine this divorced self feeling very lonely, or thinking he will not be comfortable alone, and will miss his children. Possible selves evolve and change over time in response to experiences, events, and developmental changes.

The Cognitive-Integrative (C-I) perspective (Berlin, 2002) differs from classic cognitive theory in its integration of objective interpretation, although it also retains the subjective elements of classic cognitive theory. Similar to classic cognitive theory, C-I sees individuals as constantly seeking information and meaning of their daily events to

compartmentalize the internal and external experiences in order to create a sense of predictability and further individual goals. The meaning a person makes of an event is shaped by the stimulus event or informational cue, and by what he has already learned. Berlin (2002) states:

The conclusions that we draw from our experiences, the meaning we make from them, our sense of who we are, how things are going, how we stand in relation to others and the world – are influenced by two major factors: the nature of the information that we encounter and our own patterns or systems for organizing and classifying events. (p. 3)

The Cognitive-Integrative perspective, added to our understanding by integrating both subjective and objective interpretation. There is no objective quality to what happens in the mind, we can neither always control things in our environment, nor can we simply change our thoughts to make that environment easier to handle. The mind and meaning made is subjective and based off the events or cues we are given. For example, it is not be possible to change the fact that sexual dysfunction may occur due to the cancer treatments despite a man's proactive approach to maintaining healthy sexual function. Changing the way he thinks about his sexual dysfunction will not necessarily change the physiological response brought on by treatments. However, what he chooses to do with that information and the use of other selves that have been competent in managing challenging situations can be accessed to avoid further self blame or depression. Berlin states "what each of us experiences as our self in any situation is some ensemble of memory elements – integrations of images, sounds, feelings, abilities, and motivations" (Berlin, 2002, p. 94). She claims that we make meaning in two ways; first through mental structures (schemata) and through the information or event we are

trying to make meaning of (e.g., cancer). The self is part of the mental structure and the sexual self is part of this. The concept of self-view supports the idea that we are made up of many selves that delicately dance with our learned schemata, implying that change could be made by challenging old and learning new schemata to develop our selves. The self-view acts as a lens through which a person perceives, organizes, and interprets self-relevant information and retrieves these experiences through the organized schemata (Cyranowski & Andersen, 1998; Kelly, 1995; Markus, 1977; Markus & Zajonc, 1985).

The cyclical conceptual model of the sexual self in young adult cancer survivors.

The concept of the sexual self as developed by this researcher for this study is constructed from a cognitive theory approach. It includes a “cognitive view about sexual aspects of oneself [e.g., desirability, femininity/masculinity, sexual functioning]; it derives from the past experiences and manifests in current experience, and it guides” (Andersen & Cyranowski, 1994, p. 1079) the processing of the current experience of sexual information. The sexual self, as claimed by Andersen and Cyranowski (1994), is related to intrapersonal and interpersonal aspects of sexuality. However, this model expands on the cognitive concept of sexual self schemata (Andersen & Cyranowski, 1994) to involve a working cyclical interaction of three components: sexual esteem, sexual affect/feelings, and sexual function and behavior (Figure 1).

This cyclical model in young adult cancer survivors includes a fourth component, the event of the experience of cancer as information that must be processed and absorbed into the sexual self. The sexual self, as all selves, can be flexible, cohesive, differentiated, and multifaceted and will gain knowledge and adapt based on experiences in the environment and

relationships. However, depending on both the nature of the cancer information and the meaning made of it, there can be a detrimental effect (Berlin, 2002) (Figure 2).

Berlin (2002) reports that people who identify a greater number of self-concepts and relative independence among them can better adapt and withstand the emotional and physical impact that negative life events may create. Negative information (e.g., cancer) can be an assault to the sexual self, as some may interpret the changes that incur as a problem. A positive sexual self may remain intact or not be negatively affected despite information provided by a cancer diagnosis and treatment, and the person would continue to have the hope of possible sexual selves for the future.

Events and information that can affect the sexual self.

The cycle begins for a young adult with the uncontrollable event of a cancer diagnosis providing information that influences, among other things, a young adult's sexual self. Many of the treatments directly affect sexual functioning and this changed functioning is objective information in itself. However, her interpretation of the sexual dysfunction, feelings about sexuality, including distress, may further impact sexual functioning in a negative, positive, or neutral way. New information has to be absorbed into the sexual self through the sexual schemata. The sexual self could stay stable or could experience distress according to the meaning made of the sexual dysfunction (for example). Very simply, the external events or information that affect sexual function are often ones that are out of the woman's, or man's control. Cancer and its treatments can be a direct attack on the young adult's sexual response cycle and ability to experience desire, arousal, and orgasm. One young adult may get this information (sexual dysfunction) and interpret it through a positive sexual esteem ("I'm just

as sexy even though my desire for sex has changed”) and experience low distress because of this positive sexual esteem, in spite of the sexual dysfunction. It is the sexual function or physical changes that the young adult would need to make sense of and how they might adapt, adjust, or display maladaptive thoughts towards these changes. Alterations in a person’s sexual self perception negatively affect the quality of life of cancer survivors (Ferrell & Dow, 1997; Hughes, 2000; Katz, 2005; McKee & Schover, 2001; Prieto et al., 1996). A negative sexual self would consist of low sexual esteem, high sexual distress, and low sexual function.

Sexual esteem.

The cancer event information enters the cycle and is interpreted by the survivor’s sexual esteem. Sexual esteem, or how one thinks about one’s sexuality, is formulated as a set of sexual self-schemata (Andersen & Cyranowski, 1994). This sexual self-esteem includes schemata of judgments about oneself in the area of sexuality, values, and cultural influences that have created and influenced how an individual evaluates himself as a sexual being. Our sexual esteem or schemata about our sexuality (e.g., “I am not attractive and will never be,” “I am loveable and desirable,” or “Being lesbian/gay is not okay”) are learned memory patterns (memories established from previous experiences and information that shape and influence the way we interpret current information) and attitudes developed through repeated encounters with similar experiences, perceived good or bad sexual experiences, and/or religious experiences or beliefs. For example, when a man is experiencing negative thoughts about his sexuality, he may experience depressive symptoms such as low sexual desire and negative feelings regarding sexuality and then may generalize that he is not a sexually desirable person. When the sexual self-schemata are positive, the man may have greater desire

for sexual expression. He may be willing to explore his role as a sexual partner and may take a greater interest in expressing his sexual self both overtly and covertly.

In a study by Cyranowski and Andersen (1998) assessing women's sexual self-schema, two positive aspects (romantic/passionate and open/direct self-views) and one negative aspect (embarrassment or conservatism) were identified. These negative and positive aspects of the schema were then examined to see if either acted as a deterrent or incitement to sexual expression. The women who expressed positive schemas reported sexual behaviors more positively and expressed higher levels of sexual arousal than those with a more negative schema. Quinlan and Haccard (2006) conclude:

The way in which possible selves influence behavior is thought to depend on the way in which they are evaluated. Negatively evaluated selves engage avoidance motivational systems to prevent the realization of “feared possible selves,” whereas positively evaluated selves engage an approach motivational system to promote the realization of “hoped for possible selves”. (p. 561)

Therefore, the negative or positive thoughts that are retrieved from the sexual esteem influence feelings and behaviors (Figures 1 & 2) (Cyranowski & Andersen, 1998; Nobre, 2003). This would seem to imply that a young adult with a low sexual esteem, prior to cancer, appears to be at greatest risk for sexual difficulties. She would have more difficulties because she generally is less romantic/passionate in her emotions, less open to sexual experiences, and more likely to have negative feelings about her sexuality (Andersen & Cyranowski, 1994). Thus, in the context of cancer - with disease or treatment factors causing direct changes to the sexual body or sexual responses - we might conclude that young adults

with low sexual esteem are at greater risk for sexual difficulties and a negative sexual self perception.

Distortions in thinking and denial may also be evident in young adults' perceptions of their sexual lives. Some may ignore the impact of an illness on sexual function, or their intimate relationships, until they are confronted with a problem, such as the young woman who after a colostomy never undresses in front of her partner and makes love wearing a nightgown to avoid being reminded of her cancer. For others, wearing a nightgown or lingerie may be what helps them feel sexy and therefore, it isn't about the avoidance of being reminded about cancer but rather finding ways that help her feel sexy. A young adult might also refuse to think about sex at all or say "That should be the last thing on my mind", "I should just be happy to be alive". This may also be to dismiss the sexual side effects they are experiencing or not have to acknowledge and work through these effects. "Patients who have been sexually active and functional until an illness often claim afterward to have no further interest in sex. Men are particularly likely to deny all sexual desire when a disease impairs erections. Women seem more vulnerable to illnesses that affect their physical appearance" (Schover, 1999, pg. 72). Denial can also be used in a constructive way to improve the way he feels about himself and remains sexually and intimately connected, but can be harmful if he "projects all sexual pleasure to avoid confronting the effects of illness" (Schover, 1999, p. 73).

Sexual schemata that may present in individuals who are experiencing sexual problems might include the following:

1. Women with vaginal dryness or vaginal stenosis are viewed as non-sexual to their partner and an embarrassment over their sexual performance difficulties.
2. A bad sexual performance means that libido and sexual function is permanently damaged due to induced menopause, hormonal changes, or disfigurement and the assumption they are not satisfying their partner.
3. Sexual performance difficulties may mean a loss of femininity or masculinity.
4. A negative body image

The negative automatic thoughts associated with the above examples may be:

1. Vaginal dryness: “I’m not getting wet,” “I’m not able to get turned on”.
2. Eventual disappointment assumptions “he/she is not enjoying this, he/she must be sexually frustrated”.
3. A sense of shame about potential failure: “I’m less of a woman because I have no desire”, “What is she/he thinking about me?”
4. Negative body image due to thoughts of “being deformed” “who will want me with my body so scarred”, “I will never be desirable”.

Sexual affect (sexual distress).

The cycle continues with sexual affect, or feeling, that is influenced by sexual esteem. The affect may be positive or negative in the form of distress. Sexual distress is experienced in response to negative thoughts about one's sexual self-worth; how one feels about sexual function or dysfunction; anxiety, depression, excitement, and sexual pleasure that arises from sexual function and dysfunction. Heiman and Rowland (1983) and Beck and Barlow (1986) found that sexually dysfunctional subjects reported significantly more negative affect (e.g.,

sadness) or thoughts of negativity (e.g., “I am worthless in bed”) during erotic exposure.

When negative affect in sexually functional individuals has been manipulated, a delay in subjective arousal occurs (Meisler & Carey, 1991), and individuals experience a decrease in firm erections (Mitchell, DiBartolo, Brown, & Barlow, 1998). As a young adult seeks meaning through his/her sexual schemata and sexual esteem after a diagnosis of cancer, the thoughts that arise can create negative or positive feelings. Feelings that might be associated with sexual esteem include anxiety, fear, sadness, guilt, arousal or “being turned on,” sensuality, and happiness.

Not all young adult cancer survivors identify high distress, even though it is assumed that most will experience decreased fertility and possible decreased sexual function from treatments (Skinner et al., 2007; Zabora et al., 2001; Zebrack, 2004). Although distress and stress are prevalent in survivorship, the stress (or lack of stress) of cancer does not fully explain all sexual outcomes. A correlation of self-schema with sexuality outcomes and sexual self-schema as a predictor for sexual problems in women following cancer treatments has been reported (Andersen, 1999; Andersen & Cryanowski, 1994). Andersen (1999) reported in 61 gynecologic cancer survivors, sexual self schema accounted for 28% of the variance in predicting sexual responsiveness and sexual behavior.

The C-I perspective would explain the difference in distress levels among young adults through the way each makes meaning out of the cancer experience and their sexual self through the retrieval of previous thoughts and experiences from their environment. Individuals who have had negative perceptions of their sexual self prior to cancer may experience an increase in negative thoughts as it relates to their sexuality. For example, a

woman who has had a limb amputation or resection might think,: “Who will want me now, especially since I look like a freak.” A woman with a positive sexual schema prior to cancer may think, “If he/she doesn’t accept me, then he/she isn’t worth being with anyway.” Some individuals are far more vulnerable to damage than others, depending upon their previous and current experiences of their sexual self and the schemata that they retrieve to make meaning of the physical and emotional changes that cancer creates (Mayers, Heller, & Heller, 2003).

Sexual behavior and function.

The cycle of sexual self culminates in sexual behavior and function. Sexual behavior or sexual function expresses the sexual thoughts and feelings through behaviors like kissing, having sex, masturbating, putting on makeup, and being intentional about looking nice. Sexual behaviors may also include negative ones such as isolating oneself from any intimate or physical contact, difficulty with sexual function due to low sexual esteem and high sexual distress, anorgasmia from anxiety about performance or pain, or sexual aversion. Positive sexual behavior that results from a positive sexual esteem and positive affect reflects an overall more positive sexual self.

Sexual dysfunction in the broad sense may be defined as any disruption to sexual interest or activity that results in distress. The inability to engage in a desired sexual activity may be due to physical, psychological, emotional, or biological reasons. Additionally, strained or negative relationships may also affect sexual function. Sexual dysfunction is not a life or death issue, but it is a very real quality of life issue for many cancer survivors and can contribute to stronger feelings of depression, anxiety, or low self-esteem (Evan, Kaufman, Cook, & Zeltzer, 2006; Pendley, Dahlquist, & Dreyer, 1997; Zebrack, Foley, Wittman, &

Leonard, 2009). Therefore, satisfactory sexual function among cancer survivors would be the ability to engage in any desired sexual activity. Cancer treatments can directly and indirectly impinge upon sexual function. Any changes in sexual responses, such as decreased libido, are then interpreted, and the meaning of the change within her/his sexual esteem or schemata is incorporated into the sexual self. A young woman may or may not experience any change in affect or sexual behavior if her sexual schemata is able to incorporate meaning that is not distressing, such as “I know this change is just temporary” or “I will be able to find other ways of pleasure.” Her sexual schemata may be that changes are acceptable and she is competent at finding new ways of self-pleasure. These positive thoughts may lead to calm feelings and low sexual distress, as well as, the ability to respond to her partner’s approach, and pursue sexual activities or experiences that are pleasant to her.

To summarize, the cyclical model of a positive sexual self in a young male diagnosed with colon-rectal cancer might be expressed as:

1. Information or Event: A side effect of the cancer treatments, such as a weaker erection, is experienced and cues the information to be interpreted;
2. Sexual Esteem: The external event filtered through the schema of a positive sexual self leads to an interpretation about the weaker erection, such as coming from a schema of competence, “I am competent and can be creative about how to manage this”;
3. Sexual Affect: These thoughts of competence lead to a feeling, such as relaxation and low sexual distress;

4. Sexual Behavior and Function: The thoughts of competence also leads to an increase in desire and may lead him to choose to engage in behaviors that indicate to his partner an interest in being intimate, such as initiating sexual play, or asking for more foreplay; and
5. Strengthens or threatens the sexual self: The cycle continues to repeat itself. If distress is present it will repeat until there is recognition of distress or a positive resolution is found and the thoughts or schemata triggering the negative or positive emotional and behavioral responses are evaluated and changed.

In the situation described above, the young adult is displaying comfort and competence in sexual contact with his partner, affirming his schema of self-competence, and creativity. If he encounters any other sexual difficulties or dysfunctions, he would go through this cycle again and reevaluate that event and its meaning in the same way, possibly retrieving a different schema or sexual esteem that might bring about a different behavior and result.

Summary

Cancer can be an assault to the sexual self. Although limited literature exists about the sexual health of young adult survivors, cancer survivors do experience an increase in sexual dysfunction whether related to biological, physiological, or psychological problems. Young adults are often at the prime of psychosexual development and exploration, and are continuing to establish their identity as sexual beings. Cancer and its treatments may directly and/or indirectly interfere with a young adult's sexual esteem, sexual affect and sexual behavior. With already increased risks of psychosocial distress, infertility, body image disturbances, and poorer quality of life, it is essential that oncology providers understand the implications of

cancer and its treatments on the young adult cancer survivor in order to improve the sexual self and therefore, quality of life. In order to better understand the experience of a young adult cancer survivor and the impact the diagnosis, treatments, and sexual dysfunction have on sexual esteem, sexual distress and sexual behavior, this research explored the sexual self of young adults as compared to their healthy peers.

A background on the various aspects of how cancer and its treatments may influence sexuality was provided. The conceptual model of the sexual self along, with the make-up of the sexual self's three domains, quality of life and psychological distress were identified and literature provided to further the readers understanding. A cognitive integrative perspective was utilized to describe the development of the sexual self and the possible way the event of cancer can influence or change a young adult cancer survivor's sexual self as compared to their healthy peers. The variables in the study were conceptually defined along with the theory and literature to support them. Cognitive theory and the cognitive integrative perspective were drawn from for this study.

Chapter Three will describe the study's methodology.

Chapter Three

Methodology

This chapter presents the design and methodology of the study, the study population, and the instruments chosen to assess the variables, as well as the data collection and analysis plan used to test the hypotheses. The purpose of this study was to investigate the impact of cancer and its treatments on the sexual self of young adult cancer survivors as compared to that of their healthy peers. Exploring whether there is a difference between the sexual self of young adult cancer survivors and their healthy peers will begin to address the question: Does cancer disrupt the development of the sexual self and is there an effect on the cancer survivor's quality of life?

Introduction

A cross-sectional survey design utilizing a multi-modal method of data collection was utilized. A multi-modal approach was used for “corroboration as well as completeness” (Padgett, 2008, p. 227) in gathering information that was testable and measurable and enriching this data with the exploration of the young adult's experience of the problem. “The ecological validity of a quantitative study can be enhanced considerably by grounding the study in qualitative interviews and observation before and/or after” the quantitative data is gathered (Padgett, 2008, p. 224). Positioning the focus group after the quantitative information is gathered supports and enlivens the study's data (Padgett, 2008). The data was collected through a demographic questionnaire and eight standardized instruments that measure psychological distress, quality of life, and the various aspects of the sexual self for the young adult survivor and the healthy peer. The young adult cancer survivors were administered a second quality of life scale specific to cancer, titled The Impact of Cancer

Scale. Qualitative information was collected on the young adult cancer survivors through a semi-structured telephone focus group.

Quantitative Data Collection, Measures, and Procedures

This quantitative survey was offered online via a secure website with the option of a hard copy mailed to the participant. The sample frame was young adults between the ages of 18 and 40, within two to five years of their initial diagnosis (allowing for individuals who have recurrent or metastatic disease to participate), who resided in the US or Canada, and were referred to the study by national young adult support programs (e.g., Planet Cancer; Real Time Cancer; Fertile Hope; The Ulman Fund; I'm Too Young For This).

A website was developed by the researcher to provide information on the researcher and the study with a direct link to the online study or direct contact information to the researcher to receive a paper copy. Survivor participants were made aware of the study through various national young adult cancer survivor not-for-profit organizations announcing the study on their websites and through e-mail blasts. The websites and email blasts contained a description of the research, the researcher, and a link to the website www.sexualselfandcancer.com. The "I'm Too Young For This" organization had the researcher on their weekly radio show and asked questions about the study, providing the study website to listeners and also on their website.

Participants viewed an online letter explaining the study, so that, only those interested were known to the researcher. The healthy peers were recruited utilizing a snowball sampling technique, requesting that survivors provide the survey link to at least two healthy peers with

no known history of cancer. The sample size desired was a minimum of 150 young adult cancer survivors and 150 young adult healthy peers.

Hypotheses and Research Question

This research was driven by two quantitative hypotheses and one qualitative question.

H1: Controlling for current age, young adult cancer survivors will experience more negative sexual selves than their healthy peers; that is they will have higher sexual distress, lower sexual functioning, and lower sexual esteem. **H2:** Controlling for current age and age at diagnosis, the more negative the sexual self in a young adult survivor, as indicated by higher sexual distress, lower sexual esteem, and lower sexual function, the higher the psychosocial distress and the lower the overall quality of life. **Qualitative question:** What was the young adult's experience of cancer and how did it affect his/her sexual self?

Variables and Quantitative Measures

Disease.

Disease was measured through a Yes/No format inquiring whether the young adult responding did or did not have a diagnosis of cancer. Disease was identified as the independent variable in hypothesis 1. Participants identified themselves as either having had a history of cancer, or having no history of cancer as the first question of the survey. Based on the response, the participant was presented the survivor or healthy peer survey.

Sexual Self.

The sexual self was conceptually defined as a working interaction of three components: Sexual Function, Sexual Esteem, and Sexual Distress. A negative sexual self would be low on sexual esteem, high on sexual distress, and low on sexual function. The

sexual self was the dependent variable in hypothesis 1 and the independent variable in Hypothesis 2. The sexual self was operationalized by four standardized instruments.

Sexual function.

Sexual function was defined as the ability to successfully engage in sexual activities. A dysfunction was a disturbance to any component of the sexual response cycle (sexual desire, sexual arousal, orgasm, as well as sexual pain) and that was distressing to the person.

The Female Sexual Function Inventory.

The original scale, Female Sexual Function Inventory (FSFI) was modified, with permission from the authors, to assess both male and female sexual function and was titled in this study The Sexual Function Inventory (SFI). The SFI is a 19-item questionnaire designed to assess the key dimensions of sexual function (desire, arousal, lubrication, orgasm, satisfaction, and pain) (Rosen et al., 2000; Wiegel et al., 2005). The scale was modified to include males by adding the word erection in the questions that inquired about lubrication. All other questions were gender neutral in their sexual function reference. The scale was divided into six domains: desire (D), arousal (A), lubrication (L), orgasm (O), satisfaction (S), and pain (P). Each item was scored with a 5- or 6-point Likert scale. The scores varied from 0 to 5 or 1 to 6, depending on the domain. The maximum score for each domain was 6 and the maximum total score was 36. A total score more than one standard deviation below the mean of a normal population (25.2) (as reported by Rosen et al., 2000) was considered “abnormal.” The FSFI has good reliability with Cronbach’s alpha values of 0.82 and higher and has demonstrated the ability to discriminate between clinical and nonclinical populations ($p \leq .001$) (Rosen et al., 2000).

The individual domain scores and overall score of the SFI was obtained using the formula outlined in table 3.1 by the authors of the scale. For individual domain scores, individual item scores were added and the sum is then multiplied by the domain factor. To obtain the overall scale score, the six domains were added together. A score of zero in the individual domains indicate the participant reported having no sexual activity in the past month.

Table 3.1

Scoring of Sexual Function Inventory

Domain	Questions	Score Range	Factor	Minimum Score	Maximum Score
Desire	1,2	1-5	0.6	1.2	6.0
Arousal	3,4,5,6	0-5	0.3	0	6.0
Lubrication/Erection	7,8,9,10	0-5	0.3	0	6.0
Orgasm	11,12,13	0-5	0.4	0	6.0
Satisfaction	14,15,16	0 (or 1) – 5	0.4	0.8	6.0
Pain	17,18,19	0-5	0.4	0	6.0
Overall Scale Score Range				2.0	36

Sexual esteem.

Sexual esteem was defined as cognitive appraisals and attitudes toward one's self along with the quality of sexual schemata. Sexual esteem may also be seen as a generalized tendency to positively evaluate one's own capacity to engage in healthy sexual behaviors and to experience one's sexuality in a satisfying and enjoyable way (Snell et al., 2001). Sexual esteem was measured using two scales: 1) the Sexual Esteem Scale (Snell, 2001) and 2) The Sexual Self–Schema Scale (SSSS) for both women and men (Andersen & Cryanowski, 1994; Andersen et al., 1999).

The Sexual Esteem Scale.

The Sexual Esteem Scale (Snell, 2001) is a 10-item 5 point Likert subscale of the Sexuality Scale. Answers, which are added together for total score, range from Agree (5) to Disagree (1) where higher scores correspond to greater sexual esteem. Factor analysis confirmed that the items on the Sexuality Scale form three conceptual clusters, sexual esteem, sexual depression and sexual preoccupation, that correspond to these three discrete concepts with the sexual esteem subscale demonstrating a Cronbach's alpha of 0.92 (Snell, 2001). With permission from the author, the subscale of Sexual Esteem on the Sexuality Scale was utilized and it has been reported that subscales can be used independently without effecting reliability (Snell, 2001).

Sexual Self-Schema Scales (SSSS).

It has been reported that men's and women's sexual schema are different and a specific scale for each have been developed (Andersen & Cyranowski, 1994) and were utilized in this study: The Men's Sexual Self Schema Scale and The Sexual Self Schema Scale – Women's Form. The Sexual Self Schema Scale (for men and women) are well utilized, unobtrusive adjectival inventories that measures ones' self concept as a "sexual person." It consists of a 45-item form for men and a 50-item form for women. Items do not explicitly refer to sexuality. Each adjective is rated on a 6 point rating scale. Scores from these individual measures were combined to create a composite score of sexual schema for ease of analysis.

The Men's Sexual Self Schema Scale (MSSSS) (Andersen et al., 1999) is a 45-item trait-adjective rating scale that is commonly used to assess sexual self perceptions in men. It is

a reliable, unobtrusive measure with strong evidence of construct and predictive validity that measures a man's cognitive generalizations about sexual aspects of himself. Studies of test-retest ($r = 0.81$) and internal consistency reliability and validity studies of factor analysis, internal structure, content, convergent and discriminate validity, process, group difference and change were performed. A factor analyses indicated three construct dimensions (full scale Cronbach's alpha = 0.86): Factor 1. passionate – loving (Cronbach's alpha = 0.89); Factor 2. powerful – aggressive (Cronbach's alpha = 0.78); Factor 3. open-minded-liberal traits (Cronbach's alpha = 0.65) . This instrument has been shown to be a reliable and valid assessment of a man's sexual schema formed by past sexual experience, current sexual experience, and a predictor of future sexual behavior. Scoring the MSSSS, utilizes a 6 point Likert scale to rate their view of their sexual self, 0 (*Not all descriptive of me*) to 6 (*Very descriptive of me*), the higher the sum scores on each factor the higher the man's sense of a positive sexual self.

The Sexual Self Schema Scale – Women's Form (Andersen, & Cryanowski, 1998) is a well utilized, unobtrusive 50 item trait-adjective rating scale to assess a woman's sexual self schema. Factor analyses indicated that women's sexual self views are composed of three factors, three dimensions of sexual-self views which include two positive aspects (romantic/passionate and open/direct self views) and one negative aspect (embarrassment/conservatism) which acts as a deterrent to sexual expression (Andersen & Cyranowski, 1994). Participants rated the 50 trait adjectives on a Likert scale ranging from 0 (*not at all descriptive of me*) to 6 (*very much descriptive of me*). Internal consistency (Cronbach's alpha = .82) and 2-week test-retest reliability ($r = .91$) estimates were high. The

higher the sum of factors 1 and 2, the higher positive sexual self the woman has and the higher the sum of factor 3 the higher the negative sexual self perception. Total sexual self schema scores are found by subtracting the sum of Factor 3 from the sum of Factors 1 and 2, $SSS = (\text{Factor 1} + \text{Factor 2}) - \text{Factor 3}$. Scores can range from -42 to 114.

Both the Men and Women Sexual Self Schema Scales have been shown to unobtrusively differentiate between men/women with a positive sexual-self schema and men/women with a relatively more negative sexual schema (Andersen & Cyranowski, 1994; Andersen et al., 1999). The former category is associated with a greater likelihood to experience positive emotions in association with sexual information, while the latter category is more likely to express negative or conservative attitudes towards sexual matters. Positive (or higher) schema scores have reliably shown to reflect a more positive and higher levels of sexual arousal as well as predict differences in sexual activities between positive and negative schema groups (Andersen & Cyranowski, 1994).

Sexual affect (Sexual distress).

Sexual affect was defined by how a person thinks and therefore feels about his/her sexuality and the influence it has on his/her sexual function. This was quantified through the amount of sexual distress (or negative thoughts about one's sexuality) present in participants. Sexual distress was measured by the Female Sexual Distress Scale – Revised (FSDS-R) and, with permission from the authors, adapted to measure sexual distress in both females and males.

The Female Sexual Distress Scale Revised.

Female Sexual Distress Scale Revised (FSDS-R) was adapted, with permission and by suggestion from the scale authors to read The Sexual Distress Scale-R (SDS-R) in order to include males. Although there is not any studies showing the validation of the instrument when used with men, the FSDS-R, titled in this study as the SDS-R, was designed specifically by the authors to be gender neutral in its language and assessment and therefore, nothing but the title of the instrument needed to be adapted (email communication, Leonard Derogatis, May, 2008). The FSDS-R measures the concept of sexually related personal distress with a Cronbach's alpha coefficient of > 0.86 and has demonstrated good discriminant and construct validity (Derogatis et al., 2007). The FSDS-R, a 12-item instrument, was created to measure a woman's feelings concerning distress about her sex life, assessing frustration, worry, guilt, unhappiness, embarrassment, stress, and anger using a 30-day recall period and a 5-point Likert scale (0=never to 4 =always). Responses were summed for an overall score with a score of 15 or higher indicating sexual distress. The authors of the scale used the guidelines of the American Psychiatric Association on personal distress to determine that a sexual problem of desire, arousal or orgasm was considered distressing (higher than 15) and is associated with personal distress.

Psychological distress.

Psychological distress is an aversive response to perceived internal and/or external stressors, which leads to actions aimed at addressing, adjusting to, or ignoring stressors. Psychosocial distress was measured with the Brief Symptom Inventory (BSI) (Derogatis & Melisaratos, 1983).

The Brief Symptom Inventory.

The BSI is a 53-item scale of self-reported psychological symptoms experienced during the previous seven days. Nine symptom dimensions are measured using items rated on a 5-point Likert scale from *not at all* to *extremely*. One global index was used in the analysis: the Global Severity Index (GSI) with a test-retest coefficient of 0.90. The BSI has been reported to be valid and reliable (Derogatis & Melisaratos, 1983). A high score is interpreted to mean a high level of psychosocial distress in all the BSI scales.

Quality of life.

Quality of life (QOL) is an individual's ability to function physically, emotionally, and socially within his/her environment at a level consistent with his/her own expectations (Church, 2004). QOL was measured in both samples using the Short-Form-36 (SF-36) and survivors were also asked to complete The Impact of Cancer Scale (IOC). These variables were the dependent variables in hypothesis 2. To differentiate between them in the data analysis, SF-36 will be labeled as "overall quality of life" and the IOC will be labeled as "perception of cancer on quality of life".

SF-36.

The SF-36 is a reliable and valid 36 item questionnaire that yields an eight-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures (Ware, 2000). The two SF-36 summary indexes, mental competency and physical competency are norm-based to the general U.S. population with a mean of 50 and a standard deviation of 10 (Ware & Sherbourne, 1992; Ware, 2000). Cronbach's alpha coefficients have been found to have values that range between 0.73 and

0.96 across different cancer groups. Standard errors of measurement, 95% confidence intervals for individual scores, and distributions of change scores from test-retest and one-year stability studies have been published for the eight SF-36 scales and for the two summary scores (Brazier et al., 1992; Ware et al., 1993; Ware et al., 1994). Studies support that the intended meaning of high and low SF-36 scores are valid as identified in the original user's manual and have consistently shown content, concurrent, criterion, construct, and predictive evidence of validity (Ware et al, 1993; Ware et al., 1994).

The Impact of Cancer Scale.

In addition to the SF-36, the Impact of Cancer Scale (IOC) was utilized to measure several factors of quality of life in the long-term survivors (Zebrack et al., 2007). The IOC is a 41 item 5-point Likert scale questionnaire designed to assess multiple factors of quality of life specific to the experience of cancer on an individual that is a long term survivor. This is important because many of the quality of life scales and measures of health status fail to identify the differences between a long term survivor and a healthy individual (Ganz et al., 1998; Zebrack et al., 2006). The scale's 41 items are comprised of 10 subscales (health awareness, body changes, positive and negative self-evaluation, positive and negative life outlook, life interferences, value of relationships, meaning of cancer, and health worry). All items were scored on a 5-point Likert-type scale ranging from *Not at all* to *Very Much*. The scale was put into two subscales, Positive Impact and Negative Impact. Higher scores indicated greater impact on each of the subscales.

The IOC is a newer scale but,

Used as a compliment to other health status and QOL instruments [such as the SF-36], the IOC has the potential to measure specific areas of long-term cancer survivors' lives. Given 10 content areas specific to the survivorship experience, IOC subscales have the potential to be predictive of other outcomes of interest, such as psychological well-being or mental health status. (Zebrack et al., 2006, p. 417)

Internal consistency has been shown to be good with the IOC. Adequate concurrent validity when compared with the SF36, Quality of Life – Cancer Scale (QOL-CS), and Post Traumatic Growth Index (PTGI) was found. Strong construct validity has been shown. Factor loading and measures of internal consistency showed adequate Chronbach's alphas in all subscales: Physical subscale α ranged from 0.80 to 0.84; Psychological subscale α ranged from 0.72 to 0.89; Existential subscale α ranged from 0.73 to 0.82; Social subscale α of 0.67 to 0.99; Meaning of Cancer α of 0.79; Health Worry α of 0.77.

Control variables.

Current age, reported by both survivors and healthy peers, along with age at diagnosis as reported by the survivor participants was collected in numeric form on the demographic questionnaires (Appendix A & B).

Qualitative Methodology

This research study utilized a QUANTqual methodology in gathering data through the use of several reliable and valid surveys and the use of a telephone focus group with randomly selected young adult cancer survivors. A QUANTqual study implies that the majority of data gathered on participants was quantitative in nature, with qualitative data gathered to “enliven

and illustrate” (Padgett, 2008, p. 225) the quantitative findings. The focus group interview was guided by the adapted McGill Illness Narrative (2006) with ten randomly selected study survivor participants who identified they would be willing to be included in a focus group. Of these ten, eight participated in the focus group. The focus group was conducted via a telephone conference call with the selected participants in order to gather a further understanding of their knowledge and experience of cancer and its influence on their sexual self. The qualitative question explored through the use of the McGill Illness Narrative was “What was the young adult’s experience of cancer and how did it affect his/her sexual self”?

A telephone focus group was chosen as the qualitative methodology for several reasons. First and foremost, the nature of research is exploring a very personal topic and was asking for highly personal disclosure. Recent research has shown that focus groups on the telephone have been able to elicit more information on sensitive topics than those done face to face (Frasier et al., 2010). Second, based on this researcher’s professional experience, she knows this population to be very transient and to have both spontaneous and hectic schedules. Trying to coordinate face to face focus groups with the participants would have been challenging, given that travel and work schedules might have competed. With participants on the telephone, they could speak from the hospital (which one participant did), their home, their car, or their office allowing for maximum flexibility.

Sample.

Ten young adults from around the United States and Canada, who reported they would be willing to participate in the focus group, were randomly selected. Participants’ ages ranged from 21 to 38 and were diagnosed with various cancers two to five years prior to completing

the quantitative survey. It was this researcher's desire to obtain a diverse sample from across the country. By hosting the focus group interview on the phone, the study was able to include young adults from various locations in the United States and Canada while capturing intimate information and dialogue with a diverse group of young adult cancer survivors.

Qualitative instrument.

The McGill Illness Narrative (MINI) is a semi-structured qualitative interview protocol designed to systematically elicit comprehensive illness narratives from participants including information on illness prototypes, phrases of distress, and explanatory models (Groleau & Kirmayer 2004). The MINI is sequentially structured with three main sections that obtain: (1) a basic temporal narrative of symptom and illness experience, organized in terms of the contiguity of events; (2) salient prototypes related to current health problems, based on previous experience of the interviewee, family members or friends, and mass media or other popular representations; and (3) an explanatory models, including labels, causal attributions, expectations for treatment, course and outcome. Supplementary sections of the MINI explore help seeking and pathways to care, treatment experience, adherence and impact of the illness on identity, self-perception and relationships with others. Narratives produced by the MINI can be used with a wide variety of interpretive strategies drawn from medical anthropology, sociology, and discursive psychology (Groleau & Kirmayer, 2004). The MINI was adapted to include "cancer" and "sexual life" as the event on which the researcher elicited information (Appendix C).

Data Plan

Quantitative analysis.

Utilizing Predictive Analytics Software, (PASW; Statistical Package for Social Sciences [SPSS] 2009) version 18 the quantitative data was analyzed through initially examining the descriptive statistics of the independent variable and then conducting a bivariate analysis on each of all of the major variables. Finally, hypothesis 1 was tested using independent t-tests, and multiple regression analysis was used to test hypothesis 2.

Qualitative analysis.

Verbatim transcripts from the audio-taped telephone focus group were coded using open coding of the content and themes (Grbich, 2007). Themes elicited from the content analysis of the focus group were summarized and examined to discuss what supported and enhanced the quantitative data gathered. In addition, data was analyzed to examine further questions or information that the quantitative surveys were not able to capture. Atlas.ti was used to facilitate the organization of the coding.

Human Subjects Concerns

All appropriate and necessary steps were taken to protect participant privacy. For the online survey, participants accessed the website (www.sexualselfandcancer.com), completed the informed consent (Appendix D & E), and then began the survey. If participants did not have Internet access or preferred a hard copy, the survey, the informed consent, and a self-addressed stamped envelope was mailed to them. This only occurred in one case. A coding scheme was used to maintain confidentiality of results for both online and mail responders; strict storing procedures were observed to maintain security of the data. Only first names (or

pseudonym given by the participant) were given during the focus group. All personal names and identifying information were removed from the transcribed data to assure confidentiality. Each participant was assigned a number, and the names of the individual participants have been disguised in the findings summary using the individual's assigned number. Information on the data security and destruction can be found in Appendix F.

Strengths and Limitations of the Design

The utilization of multiple reliable and valid standardized measures, along with participant anonymity, were strengths of this research design. In addition, gathering qualitative data on the sexual self of young adult survivors through an interview process improved the validity of the information gathered through the quantitative measures. A cross sectional design was chosen due to the ability to capture a large number of individuals' information on a single observation and is best used in exploratory studies. A cross-sectional design also allowed the researcher to capture data on attitudes and behaviors, generate hypotheses for future research and allows the data to be useful to various researchers, inside and outside of the social work profession (California State University Long Beach, n.d.).

The limitations of an exploratory study with a cross sectional design, are not being able to measure change over time, and establishing cause and effect is not possible. Increased weakness to the design was participant self-selection and self-report. Therefore, it is more likely that participants who had an interest in the sexual self of cancer survivors responded. Although improved by utilizing a qualitative interview, surveys also only provide limited subjective descriptions of what the participants experience has been. This may be particularly

true for a sensitive subject matter like sex, as the participant may not have felt as comfortable answering the questions as honestly as their experience may have been.

Summary

This chapter included descriptions of the dominant quantitative methodology and the less dominant, qualitative methodology of the study's mixed method research. The quantitative portion utilized a survey that began with demographic questions and incorporated valid and reliable scales to operationalize the study's independent variable of the sexual self and the two dependent variables of psychological distress and quality of life. The study sample consisted of 167 young adults (113 cancer survivors, 54 healthy peers).

The qualitative portion of the study used transcription of the semi-structured interviews with eight of the randomly selected young adult cancer survivors whom indicated they would be willing to participate in a focus group. The focus group was intended to elicit more specific and detailed information on the experience of being a young adult cancer survivor, changes in their sexual self, and their view of how cancer influenced their sexual self and relationships.

The next chapter will focus on the study's findings. Chapter Four will present the quantitative and qualitative findings. Chapter Five will summarize the findings, explore and interpret the relationships between the qualitative and quantitative portions of the research, and discuss the major contributions of the study along with limitations and implications for social work research and practice.

Chapter Four

Findings

This chapter will first describe the sample population of young adult cancer survivors according to their gender, diagnosis, age at diagnosis, current age, education, ethnicity/race, and relationship status. Second, the chapter presents the analyses of the quantitative data collected along with a discussion of these findings. Quantitative findings will be categorized as (a) descriptive statistics of the independent variables, that is measures of central tendency, frequencies and percentages; (b) bivariate analysis of each of all the major variables; (c) testing of hypothesis 1 using independent t-test; (c) testing hypothesis 2 using multiple regression analysis. Third, the chapter presents qualitative findings. Finally, the chapter will conclude with a summary of the quantitative and qualitative findings.

Sample Description

A convenience sample of 113 young adults (YA), currently between the ages of 18 and 40 and diagnosed with cancer 2 to 5 years ago, completed the survey for this study. A comparison group of 54 peers, with no history of cancer, completed the survey utilizing a snowball sampling technique. Snowball sampling is a non-probability technique that asks the subjects to suggest other participants who may be willing or appropriate for the study. No cases were discarded, however, it is important to note that 83% of the individuals who visited the survey site abandoned the survey, and 17% ($n = 167$) completed the survey. The sociodemographic data collected included gender, age, ethnicity/race, relationship status, highest educational level achieved, age at which the young adult was sexually active, if nonconsensual sex had occurred, and at what age. In addition, survivors were also asked to report their cancer diagnosis, age at diagnosis, treatments received, if fertility information had

been discussed by a health care provider, and if information on sexuality had been discussed by a health care provider. Qualitative data was gathered on 8 of the 10 randomly selected cancer survivors, who agreed to be part of the focus group. Five females and five males in the survivor group were randomly selected to participate in an attempt to obtain information from both genders; however, only three of the women participated in the interview. Frequency distributions, measures of central tendency, and measures of dispersion were calculated to describe sociodemographic characteristics, the dependent variable, and the independent variables using the SPSS (2009) v. 18. Qualitative data from the focus group interview was analyzed utilizing *Atlas.ti*, a qualitative data software.

Presentation of the quantitative findings.

Tables 4.1 – 4.4 illustrate the distribution of the young adult (YA) sample according to Gender, Age, Ethnicity/Race, Sexual Orientation, Relationship Status, Highest Educational level, Age YA became Sexually Active, Nonconsensual Sexual Experiences and Age, Cancer diagnosis, treatments, age at diagnosis. Table 4.5 provides a summary of statistics on the various scales. Tables 4.6 – 4.7 demonstrate the Pearson's Correlation on all variables. Table 4.8 illustrates the independent t-tests run to compare the sexual self of young adult cancer survivors to their healthy peers (H1). And Tables 4.9 – 4.12 demonstrate the multiple regressions on the independent variables sexual function, sexual esteem, sexual distress on the dependent variables quality of life and psychological distress (H2). Tables 4.13 – 4.16 illustrate additional findings.

Descriptive statistics of the sample.***Gender.***

Table 4.1 represents the distribution of the young adults by gender. Of the 167 young adults, 82.6% were female and 17.4% were male. There was no significant difference between the healthy peer and survivor groups. The survivors ($n = 167$) were comprised of 13 males (11.5%) and 100 females (88.5%). In the healthy peers ($n = 54$) the women made up 70.4% of the sample and 29.6% were male.

Age.

Table 4.1 describes the frequencies and percentages of the young adult ages represented in this study. Actual age was used in the analyses, however, age was recoded into three ordinal age groups for ease of comparison: 18 to 25, 26 to 33, 34 to 40. There was no significant difference in the representation of age between the two groups. The age group that had the largest representation was the 26 to 33 year olds in both the survivor (46.0%) and healthy peer group (48.1%). Nearly 17 percent of the survivors were between the ages of 18 to 25 and of the healthy peers, 20.4 percent were 18 to 25. The second largest age group representation were the 34 to 40 year olds, with 37.2% ($n = 42$) of the survivors and 31.5% ($n = 17$) of the healthy peers.

Ethnicity/Race.

The sample of 167 young adults included: 153 Caucasians, 12 non-Caucasians (African American, Asian Pacific Islander, Hispanic, Other). Ethnicity/Race was initially categorized as African American/Black, Caucasian/White, Asian/Pacific Islander, Hispanic and Other with the majority of respondents in each group being Caucasian/White ($n = 153$). In

Table 4.3a race/ethnicity was recoded to Minority ($n = 13$) and Non-Minority ($n = 154$) and no significant differences were found between survivors and healthy peers (Table 4.1).

Sexual orientation.

The distribution of the sample according to sexual orientation was found to be significantly different (likely due to the difference in size between the two groups), with the young adult cancer survivors' having a much larger percent of persons who do not identify as heterosexual (15.9%) compared to the healthy peers (1.9%) ($\chi^2 = 7.182$, $df = 1$, $p < .01$) (Table 4.1).

Relationship status.

The distribution of the sample according to relationship status was found to be significantly different between the two groups ($\chi^2 = 5.927$, $df = 1$, $p < .05$). Young adult cancer survivors ($n = 113$) reported a higher frequency of being single (single, dating, single/divorced) 37.2% ($n = 42$) compared to their peers at 18.5% ($n = 10$). Nearly 63 percent of the young adult cancer survivors reported they were married or in a committed partnership ($n = 71$) which was lower than their peers at nearly 82% ($n = 44$) (Table 4.1).

Highest educational level.

Highest educational level achieved was collected on all young adults with one respondent's information missing from the healthy peer group ($n = 153$). The majority of the healthy peers and survivors had completed at least a bachelor's degree. There was no significant difference between survivors and healthy peers in their education. Education was collapsed into three major categories: High school or less, College, Advanced Degree. The four "other" responses all reported advanced degrees and were recoded as such. One hundred

and six (63.5%) young adults received a college education and 59 obtained an advanced degree (35.3%) (Table 4.1).

Table 4.1

Sociodemographic Characteristics by Survivor (n = 113) and Healthy Peer (n = 54)

Variables	Survivor		Healthy Peer	
	<i>n</i>	%	<i>n</i>	%
Gender				
Female	100	88.5	38	70.4
Male	13	11.5	16	29.6
Age Range				
18 – 25	19	16.8	11	20.4
26 – 33	52	46.0	26	48.1
34 - 40	42	37.2	17	31.5
Ethnicity/Race				
Minority	8	7.1	5	9.4
Non-Minority	104	92.9	48	90.6
Sexual Orientation				
Heterosexual	95	84.1	53	98.1
Other	18	15.9	1	1.9
Relationship Status				
Single – Never Married	28	24.8	5	9.3
Dating	9	8.0	4	7.4
Married	49	43.3	34	63.0
In a committed relationship	22	19.5	10	18.5
Single – Divorced/Separated	5	4.4	1	1.8
Highest Education Level				
High School or Equivalent or Vocational or Technical School	8	7.1	1	1.9
Some College	26	23.0	10	18.5
Bachelors	42	37.2	18	33.3
Masters	28	24.8	17	31.5
Doctoral	5	4.4	4	7.4
Other	4	3.5	3	5.6

Age sexually active. (n = 166, missing 1)

The age at which the young adult became sexually active was collected and then categorized into five ordinal groups for ease of comparison: 9 to 14, 15 to 20, 21 to 26, 27 to 31, Not Applicable (N/A). Sexual activity was not defined and therefore was left to subjective interpretation. There was no significant difference found between the two groups. The majority of both the healthy peers (66.7%) and survivors (72.6%) reported sexual activity began between the ages of 15 and 20. The lowest frequency at which sexual activity began was between the ages of 27 to 31. Nearly eleven percent of the young adult survivors became sexually active between the ages of 9 to 14 and accounted for 9.3% of the healthy peers. Four of the young adult respondents reported never being sexually active (3.5%) (Table 4.2).

Table 4.2

Sexual Activity Characteristics of Sample by Survivor (n = 113) and Health Peer (n = 54)

Variables	Survivor		Health Peer	
	<i>n</i>	%	<i>n</i>	%
Age Sexually Active				
9 - 14	12	10.7	5	9.3
15 - 20	82	73.21	36	66.7
21 - 26	12	10.7	12	22.2
27 - 31	2	1.8	1	1.9
N/A	4	3.6	0	0.0
Non-consensual sex				
Yes	28	24.8	10	18.5
No	85	75.2	44	81.5
Age of Non-consensual sex				
0 - 9	6	5.3	1	1.9
10 - 20	17	15.0	7	13.0
21 - 30	2	1.8	1	1.9
Multiple Ages Reported	2	1.8	0	0.0

Non-consensual sex.

Table 4.2 demonstrates the frequencies and percentages of the young adult sample who reported an incident(s) of non-consensual sex, along with their age at the time of the incident(s). There was not a significant difference between the two groups. A total of 38 young adults reported non-consensual sexual experiences. Of the survivors, 24.8% ($n = 28$) (25 females, 3 males) reported having at least one incident of non-consensual sex compared to 18.5% of the healthy peers ($n = 10$) (8 females, 2 males). There is limited literature on male victims of non-consensual sex, but it is reported that approximately 18% of all women and 3% of all men in the United States have been a victim of rape (Tjaden & Thoennes, 2006). The data from this study reported a higher percentage rate with 23.9% of all the females and 17.7% of all the males reporting at least one incident of non-consensual sex.

Age at diagnosis and cancer diagnosis of young adult survivors.

Table 4.3 displays the frequency and percentage of the age of the young adult cancer survivors at initial diagnosis and the diagnoses reported. Age at diagnosis was used in all analyses but was recoded to ordinal groups for ease of comparison. 30.1% of the sample was between the ages of 24 to 28 years old when they were diagnosed compared to only 6.2% of the young adults diagnosed between the ages of 14 to 18 and 17.7% aged 19 to 23. Nearly twenty-six percent (25.7%) of the young adult survivors were 29 to 33 years and 20.4% were 34 to 38 at time of diagnosis. All blood cancers were grouped together to include Lymphoma, Non-Hodgkin's lymphoma, Leukemia (unspecified), Hodgkin's lymphoma, Chronic Myelogenous Leukemia and Acute Lymphoblastic Leukemia. Of the sample, the majority of the respondents reported having a blood cancer (29.2 %) or a breast cancer (31.9%).

Gynecological cancers represented (7.1%) of the young adult sample and included ovarian cancer, uterine, cervical cancer, and vulvar cancer. Other cancers represented were sarcoma (5.3%), thyroid (6.2%), melanoma (4.4%) and colon cancer (5.3%). Just over 4% of the survivor sample reported more than one incidence of a different cancer (non-recurrent) and 6.2% reported another type of cancer.

Table 4.3

Illness Related Characteristics of Survivors (n = 113)

	n	%
Age at Diagnosis		
14 - 18	7	6.2
19 - 23	20	17.7
24 - 28	34	30.1
29 - 33	29	25.7
34 - 38	23	20.4
Type of Cancer		
Blood Cancers	33	29.2
Breast Cancers	36	31.9
Gynecological Cancers	8	7.1
Sarcomas	6	5.3
Thyroid Cancers	7	6.2
Melanoma	5	4.4
Colon Cancer	6	5.3
Multiple Cancer Diagnoses	5	4.4
Other	7	6.2
Cancer Treatments Received ^a		
Chemotherapy	97	85.8
Radiation	62	54.9
Stem Cell/Bone Marrow Transplant	11	9.7
Surgery	80	70.8
Hormone Therapy (e.g., Tamoxifen)	33	29.2

^a Total greater than n = 113 and 100% due to ability to select more than one type of cancer treatment received

Cancer treatments received.

Young adult cancer survivors typically have to have more than one treatment regimen during their cancer experience. Of the 154 young adult cancer survivors, a large percent

reported having chemotherapy (85.8%) and surgery as treatments received (70.8%). Radiation was received by 54.9%, hormone therapy was given to 29.2%, and 9.7% of the young adult cancer survivors reported having a stem cell or bone marrow transplant. Other treatments received were reported by 23.9% and included interferon, Lupron injections, Herceptin, radioactive iodine treatments, Zometa, Gleevec, clinical trial medication (unspecified), immunotherapy, hormone replacement therapy for after treatment induced menopause, proton therapy, and protein inhibitors (Table 4.3).

Treatment induced menopause.

Of the 100 female young adult cancer survivors, 40% reported that they had been put into an early menopause or premature ovarian failure and 16% reported they were unsure (Table 4.4).

Fertility effects.

Table 4.4 describes the frequency and percent of the 113 young adult cancer survivors who reported that treatment had affected their ability to bear children. Nearly equal proportions of females and males reported their fertility was not affected (males, 15.4%; females, 16%). Seven males reported that their ability to have children was affected (53.8%) compared to 44% of the females. Forty percent of females and 30.8% of males reported they were unsure if their fertility was affected. Nearly 77% of the sample reported they, or their guardian (if they were a minor at diagnosis), had spoken with a health care professional about the risks to fertility, with a greater number of males reporting positively (92.3%) than females (75%). Twenty-five percent of females and approximately eight percent of males reported they or their guardians had not had a conversation with a health care provider about the risks

of treatment to their fertility. Of the 75 women who reported that a discussion on fertility had taken place, there were 61 reports that this conversation took place before treatment with nine reports that the discussion took place after treatment or they did not remember when the conversation took place. Of the 13 men, there were 9 reports that a conversation on fertility took place before treatment, while the remainder reported that it occurred during treatment, after treatment or could not recall when the conversation took place.

Table 4.4

Characteristics about Menopause, Fertility, and Discussion on Fertility by Gender

Variable	Female (n= 100)		Male (n = 13)	
	n	%	n	%
Treatment Induced Menopause				
Yes	49	40.0		
No	35	45.0		
Ability to Bear Children				
Yes	44	44.0	7	53.8
No	16	16.0	2	15.4
Don't Know	40	40.	4	30.8
Health Care Team Discussed Fertility				
No	25	25.0	1	7.7
Yes	75	75.0	12	92.3
If Yes, When did the discussion take place				
Before Treatment	61	61.0	9	69.2
During Treatment	0	0.0	4	30.8
After Treatment	6	6.0	4	30.8
Don't Remember	3	3.0	2	15.4

Statistical Analysis

Difference between groups.

The independent t-tests indicated that there were no significant differences between the sociodemographic make up of the two groups, other than relationship status and sexual

orientation. Young adult cancer survivors had a greater likelihood of being single than their healthy peers and reported a higher likelihood of sexual orientation other than heterosexual. This could be due to the difference in numbers between the groups. There was no significant relationship between current age and the three domains of the sexual self.

Independent and dependent variables.

Sexual self.

The independent variable sexual self, expands the concept of sexual self schemata to involve a working interaction of sexual esteem, sexual affect, and sexual function/behavior. It was operationalized using five scales (4 total for each gender) assessing the three domains of sexual function, sexual esteem, and sexual affect.

Sexual function.

Sexual function was measured utilizing a 19-item scale with six domains (desire, arousal, lubrication/erection, satisfaction, pain) (Rosen et al., 2000). In this scale, a 0 represents the respondent reporting that he or she was not sexually active in the past month, thus only being able to report a score for two of the questions. Scores can range from 1 to 36, with higher scores representing higher functioning. The results indicated a range in sexual functioning scores for young adult cancer survivors from 1.2 to 36.0 and for healthy peers from 4.80 to 36.0. The mean for young adult cancer survivors was 21($SD = 9.4$). The mean for healthy peers was 29.5 ($SD = 5.8$) (See Table 4.5).

Sexual esteem.

Sexual esteem was measured utilizing two scales for each gender: sexual esteem and sexual schema. The first scale (sexual esteem scale) was a ten-item scale with 0 representing

low sexual esteem and 40 representing high sexual esteem. The results indicate a range from 0 to 40 for young adult cancer survivors and 10 to 40 for their healthy peers. The mean score for the cancer survivors was 21.71 ($SD = 11.6$) compared to their healthy peers with a mean of 27.31 ($SD = 8.8$) (See Table 4.5).

The second scale that was utilized to assess sexual esteem was the gender specific Sexual Self Schema Scales. The Sexual Self Schema Scale Women's Form was a 50-item scale with 0 representing *not at all descriptive of me* to 6 *very descriptive of me* (0 to 114 possible range) and higher scores indicating a more positive sexual self schema. The Sexual Self Schema Scale for Men form is a 45 item scale with 0 representing *not at all descriptive of me* to 6 *very descriptive of me* and higher scores indicating more positive sexual self schema (possible range 0 to 162 for men). The results for healthy male peers ranged from 78 to 134 with a mean score of 104.27 ($SD = 18.14$). The results for male cancer survivors ranged from 75 to 133 with a mean score of 97.0 ($SD = 19.2$). Female healthy peer results ranged from 32 to 90 and had a mean of 62.14 ($SD = 16.3$). Female cancer survivors reported ranges from 19 to 114 and a mean of 57.04 ($SD = 18.1$). Total scores from each gender in each group (healthy peer and survivor) were combined to create a total sexual self schema score with scores ranging in survivors from 19 to 133 and healthy peers from 32 to 134. The mean score for survivors was 61.52 ($SD = 22.1$) while healthy peers had a mean score of 74.78 ($SD = 25.7$) (See Table 4.5).

Sexual affect (Sexual distress).

Sexual affect was measured with a 13-item scale measuring sexual distress with 0 representing *never* (no distress) and 4 *always* (high distress). Scores ranged for healthy peers

between 0 and 37 and survivors reported a range of scores between 0 and 52. The mean score for the healthy peer group was 9.7 ($SD = 9.0$). Young adult cancer survivors reported a mean score of 21.2 ($SD = 13.6$) (See Table 4.5).

Quality of life.

The dependent variable of quality of life was measured with two scales. Overall quality of life was measured with a 36-item scale for both healthy peers and young adult cancer survivors (SF-36). The composite scores on the general quality of life measure (SF-36) ranged from 39.6 to 55.7 for healthy peers and 39.0 to 53.3 for survivors. The mean score for survivors was 45.4 ($SD = 3.18$) and the healthy peers reported a mean score of 47.67 ($SD = 3.73$). The perception of cancer on quality of life (positive and negative) was assessed within the survivor group. Survivors completed this 54-item scale that assesses for various quality of life issues in a cancer survivor. The scale reports on two domains – positive impact of cancer and negative impact of cancer. Young adult cancer survivors demonstrated scores that ranged on the positive impact scale from 8.3 to 20.0 with a mean of 15 ($SD = 2.5$) and perceived negative impact ranged from 4.6 to 19.4 with a mean of 13.8 ($SD = 3.4$) (See Table 4.5).

Psychological distress.

The dependent variable psychological distress was operationalized through the use of a 53-item scale that measures for psychological distress. An overall raw score was utilized to measure overall psychological distress in both healthy peers and young adult cancer survivors. Psychological distress scores for the healthy peer group ranged from 0.28 to 1.9 with a mean score .73 ($SD = 0.4$). Young adult cancer survivors demonstrated scores that ranged from 0.30 to 3.1 with a mean of 1.1 ($SD = 0.6$) (See Table 4.5).

Table 4.5

Summary Statistics for Scales

	Cancer Survivor			Healthy Peers		
	Mean	S.D.	Actual Range	Mean	S.D.	Actual Range
Sexual Function	21.0	9.5	1.2 – 36.0	29.5	5.9	4.80 – 36.0
Sexual Esteem	21.71	11.6	0 - 40	27.31	8.9	10 - 40
Sexual Schema – Male	19.2	97.0	75 - 133	104.27	18.14	78 - 134
Sexual Schema – Female	57.04	18.1	19 - 114	62.14	16.3	32 - 90
Sexual Distress	21.2	13.6	0 - 52	9.7	9.0	0 - 37
Overall QOL	45.4	3.18	39.0 – 53.3	47.67	37.3	39.6 – 55.7
Perception of Cancer on QOL						
Positive	15.0	2.5	8.3 – 20.0			
Negative	13.8	3.4	4.6 – 19.4			
Psychological Distress	1.1	0.6	0.30 – 3.1	.73	0.4	0.28 – 1.9

Bivariate analysis.

Analysis of relationships between the domains of the sexual self (sexual function, sexual esteem and sexual distress) and the control variables of age and survivorship status were explored at the bivariate level to determine if there were significant linear relationships with the sexual self and/or the other variables using Pearson's correlation (Tables 4.6 and 4.7).

Pearson's correlation.

Pearson's correlations were conducted to test whether statistically significant linear relationships exist between the dependent variables, quality of life and psychological distress, and the three domains of the independent variable the sexual self. This analysis determined which variables were included in the multiple regression analysis.

1. In young adults with cancer, there was a statistically significant weak, negative linear relationship between the negative perceived impact of cancer (IOC) and the overall quality of life reported in the SF-36 ($r = -.294, p < .01$). The higher the negative perception of the impact of cancer, the lower the quality of life scores in young adults with cancer.
2. In young adults with cancer, there was a statistically significant moderate, negative linear relationship between psychological distress (BSI) and the overall quality of life reported in the SF-36 ($r = -.440, p < .01$). The higher the psychological distress, the lower the quality of life scores in young adults with cancer.
3. In healthy peers, there was a statistically significant moderate, negative linear relationship between psychological distress (BSI) and the overall quality of life reported in the SF-36 ($r = -.476, p < .01$). The higher the psychological distress, the lower the quality of life scores in young adults with no history of cancer.
4. In young adults with cancer, there was a statistically significant moderate, negative linear relationship between sexual distress (SDS) and the overall quality of life reported in the SF-36 ($r = -.317, p < .01$). The higher the sexual distress, the lower the quality of life scores in young adults with cancer.

5. In young adults with cancer, there was a statistically significant moderate, positive linear relationship between psychological distress (BSI) and the perceived negative impact of cancer reported in the IOC ($r = .534, p < .01$). The higher the psychological distress, the higher the negative impact of cancer scale scores in young adults with cancer.
6. In young adults with cancer, there was a statistically significant moderate, negative linear relationship between sexual esteem and the perceived negative impact of cancer reported in the IOC ($r = -.321, p < .01$). The lower the sexual esteem the higher negatively perceived impact of cancer in young adults with cancer.
7. In young adults with cancer, there was a statistically significant moderate, negative linear relationship between sexual function (SFI) and the perceived negative impact of cancer reported in the IOC ($r = -.339, p < .01$). The poorer the sexual function, the higher the perceived negative impact of cancer scale scores in young adults with cancer.
8. In young adults with cancer, there was a statistically significant moderate, positive linear relationship between sexual distress (SDS) and the perceived negative impact of cancer reported in the IOC ($r = .427, p < .01$). The higher the sexual distress the greater the perceived negative impact of cancer scale scores in young adults with cancer.
9. In young adults with cancer, there was a statistically significant negative linear relationship between sexual function and psychological distress reported in the

BSI ($r = -.253, p < .01$). The lower the sexual function, the greater the psychological distress scores in young adults with cancer.

10. In healthy peers, there was a statistically significant moderate, negative linear relationship between sexual function (SFI) and psychological distress in the BSI ($r = -.353, p < .01$). The lower the sexual function, the greater the psychological distress scores in young adults with no history of cancer.
11. In young adults with cancer, there was a statistically significant moderate, positive linear relationship between sexual distress and psychological distress reported in the BSI ($r = .345, p < .01$). The higher the sexual distress, the greater the psychological distress scores in young adults with cancer.
12. In young adults with cancer, there was a statistically significant moderate, positive linear relationship between sexual schema and sexual esteem reported in the Sexual Esteem Scale ($r = .417, p < .01$). The more positive the sexual schema the higher the sexual esteem scores in young adults with cancer.
13. In healthy peers, there was a statistically significant strong, positive relationship between sexual schema (SSS) and sexual esteem reported in the Sexual Esteem Scale ($r = .597, p < .01$). The more positive the sexual schema, the higher the sexual esteem scores in young adults with no history of cancer.
14. In young adults with cancer, there was a statistically significant moderate, positive relationship between sexual function (SFI) and sexual esteem reported in the Sexual Esteem Scale ($r = .497, p < .01$). The greater the sexual function, the higher the sexual esteem scores in young adults with cancer.

15. In healthy peers, there was a statistically significant strong, positive relationship between sexual function (SFI) and sexual esteem reported in the Sexual Esteem Scale ($r = .627, p < .01$). The greater the sexual function, the higher the sexual esteem scores in young adults with no history of cancer.
16. In young adults with cancer, there was a statistically significant moderate, negative linear relationship between sexual distress (SDS) and sexual esteem in the Sexual Esteem Scale ($r = -.434, p < .01$). The higher the sexual distress, the lower the sexual esteem scores in young adults with cancer.
17. In healthy peers, there was a statistically significant moderate, negative relationship between sexual distress (SDS) and sexual esteem reported in the Sexual Esteem Scale ($r = -.548, p < .01$). The higher the sexual distress, the lower the sexual esteem scores in young adults with cancer.
18. In young adults with cancer, there was a statistically significant very weak, positive linear relationship between sexual function (SFI) and sexual schema in the Sexual Self Schema Scale ($r = .209, p < .05$). The higher the sexual function, the more positive the sexual self schema scores in young adults with cancer.
19. In young adults with cancer, there was a statistically significant moderate, negative linear relationship between sexual distress (SDS) and sexual function in the Sexual Function Inventory ($r = -.388, p < .01$). The higher the sexual distress, the lower the sexual function scores in young adults with cancer.
20. In healthy peers, there was a statistically significant strong, negative relationship between sexual distress (SDS) and sexual function reported in the Sexual Function

Inventory ($r = -.682, p < .01$). The higher the sexual distress, the lower the sexual function scores in young adults with no history of cancer.

Table 4.6

Correlations of Major Variables in Young Adult Cancer Survivors

	Quality of Life	Impact of Cancer Negative	Impact of Cancer Positive	Psychological Distress	Sexual Esteem	Sexual Schema	Sexual Function
Impact of Cancer Negative	-.294**						
Impact of Cancer Positive	-.052	-.019					
Psychological Distress	-.440**	.534**	-.078				
Sexual Esteem	.109	-.321**	.050	-.142			
Sexual Schema	-.018	-.129	.096	-.151	.417**		
Sexual Function	.143	-.339**	.041	-.253**	.497**	.209*	
Sexual Distress	-.317**	.427**	-.070	.345**	-.434**	-.077	-.388**

** = $p < .01$ * = $p < .05$

Table 4.7

Correlations of Major Variables in Young Adult Healthy Peer Comparison Group

	Quality of Life	Psychological Distress	Sexual Esteem	Sexual Schema	Sexual Function
Psychological Distress	-.476**				
Sexual Esteem	.127	-.190			
Sexual Schema	.041	.112	.597**		
Sexual Function	-.224	-.353**	.627**	.274	
Sexual Distress	-.174	.268	-.548**	-.268	-.682**

** = $p < .01$ * = $p < .05$

Testing hypothesis 1.

Independent t-tests.

On average, cancer survivors and healthy peers reported similar sexual self schema scores, with no statistically significant difference found between the two groups (Table 4.8). However, young adult cancer survivors reported significantly higher psychological distress levels ($M = 1.1$, $SD = 0.6$) than their healthy peers ($M = 0.7$, $SD = 0.4$) ($t = 5.017$, $df = 137.862$, $p < .001$). Additionally, young adults with cancer reported lower overall quality of life ($M = 45.4$, $SD = 3.2$) than their healthy peers ($M = 47.7$, $SD = 37.3$) ($t = -3.918$, $df = 85.866$, $p < .001$). When exploring the domains of the sexual self, sexual function, sexual esteem and sexual distress were all significantly different between the two groups. Young adults with cancer reported significantly lower levels of sexual functioning or sexual inactivity ($M = 21.0$, $SD = 9.4$), than their healthy peers ($M = 29.5$, $SD = 5.8$) ($t = -6.918$, $df = 147.006$, $p < .001$). Young adults with cancer reported significantly lower sexual esteem ($M = 21.7$, $SD = 11.6$) than their healthy peers ($M = 27.3$, $SD = 8.8$) ($t = -3.379$, $df = 86.87$, $p < .001$) and higher sexual distress scores ($M = 21.2$, $SD = 13.6$) than their healthy peers ($M = 9.7$, $SD = 9.0$) ($t = 6.39$, $df = 144.91$, $p < .01$). Independent t-tests confirmed that there is a statistically significant difference between the sexual self of young adult cancer survivors and their healthy peers, with survivors demonstrating more negative sexual selves. Therefore, study hypothesis one, *controlling for age, young adult cancer survivors will experience more negative sexual selves than their healthy peers; that is they will have higher sexual distress, lower sexual functioning, and lower sexual esteem*, has been partially supported as age was not included in the final analysis.

Table 4.8

Independent T-tests

Name of scale	Survivors			Healthy Peers			t
	Mean	SD	Range	Mean	SD	Range	
SF36	45.4	3.2	39.0 - 53.3	47.7	3.7	39.6 – 55.7	-3.92*
Brief Symptom Inventory (BSI)	1.1	0.6	1.2 – 3.1	0.7	0.4	0.28 – 1.9	4.50*
Sexual Function Index (SFI)	21.0	9.4	1.2 – 36.0	29.5	5.8	4.8 – 36.0	-6.0*
Sexual Esteem (subscale of SS)	21.7	11.6	0.0 – 40.0	27.3	8.8	10.0 – 40.0	-3.07*
Sexual Self Schema (SSSS)	61.5	22.1	19.0 – 133.0	74.8	25.6	32.0 – 134.0	-3.32
Sexual Distress (SDS-R)	21.2	13.6	0.0 – 52.0	9.7	9.0	0.0 – 37.0	5.60*
Positive Impact of Cancer (IOC)	15.0	2.5	4.6 – 19.4	na	na	na	na
Negative Impact of Cancer (IOC)	13.8	3.4	8.3 – 20.0	na	na	na	na

*p < .001

Testing hypothesis 2.***Multiple regression.***

Hypothesis 2, *controlling for age at diagnosis, the more negative the sexual self in a young adult survivor, as indicated by lower sexual esteem, higher sexual distress, and lower sexual function, the higher the psychological distress and the lower the quality of life*, was tested by performing multiple regression analyses of the independent variables that constitute the sexual self, on the dependent variables of Quality of Life (overall quality of life and the perception of cancer on quality of life) and Psychological Distress in survivors utilizing Statistical Package for Social Sciences (SPSS, v. 18). Initially, hypothesis two called for controlling age and age at diagnosis. However, in the bivariate analysis it was discovered that

age and age at diagnosis are almost perfectly correlated (0.96). Therefore, the researcher chose to just control for age at diagnosis. Controlling for age at diagnosis was not significant with all of the sexual self domains, psychological distress, or the negative impact of cancer scale scores. However, age at diagnosis was significant with two of the sexual self domains and overall quality of life scores (SF-36), along with the positive impact of cancer scale scores.

Controlling for age at diagnosis, sexual distress was predictive of overall quality of life as measured by the SF-36 ($F = 3.974, p < .004$). The older the survivor was at diagnosis and the less sexual distress, the higher the QOL. Sexual distress was the stronger predictor ($\beta = -.345$) than age at diagnosis ($\beta = .242$) of QOL. The whole model (all domains of the sexual self) explained 20.1% of the variance in overall quality of life (SF-36).

Controlling for age at diagnosis, age at diagnosis was the only statistically significant predictor ($p < .05$), with sexual esteem trending toward significant ($p < .08$) in predicting positive perception of cancer on quality of life, as measured by the IOC scale ($F = 2.403, p < .05$). The younger the survivor was at diagnosis and the higher their sexual esteem, the higher the positive QOL of cancer survivors. Age at diagnosis was the stronger predictor ($\beta = -.244$) than sexual esteem ($\beta = .246$). The whole model explained 12.8% of the variance in the Impact of Cancer positive subscale.

Multiple regression analyses were rerun without any control variables to test the independent variables making up the sexual self on the dependent variables of overall quality of life, perception of cancer on quality of life, and psychological distress. When the models of the effect of the sexual self on psychological distress and the negative perception of cancer on

quality of life were run, both models were found to be significant. All domains, except the sexual self schema, were found to be predictive of at least one of the dependent variables.

Sexual distress was predictive of quality of life as measured by the negative perception subscale of the IOC ($F = 5.253, p < .001$). The greater the survivors sexual distress ($\beta = .319$), the lower the negatively perceived quality of life. 20.2% of the variance was explained by the whole model in the Impact of Cancer negative subscale.

Sexual distress was predictive of psychological distress with sexual function trending toward predictive of psychological distress as measured by the Brief Symptom Inventory ($F = 4.944, p < .001$). The greater the sexual distress and the lower the sexual function, the greater the psychological distress. Sexual distress was the stronger predictor ($\beta = .339$) than sexual function ($\beta = -.226$). The whole model explained 19.2% of the variance in the BSI.

Therefore, hypothesis two, *controlling for age at diagnosis the more negative the sexual self, the higher the psychological distress and lower the quality of life in survivors*, has been partially supported. The partial support is in part that age at diagnosis was not included in the model due to not being statistically significant and part due to not all aspects of the sexual self being statistically significant predictors for both of the models.

Table 4.9

Controlling for age at diagnosis on Overall QOL (SF-36)

SF-36	B	Beta	p
Constant	42.634		.000
Age at Diagnosis	.131	.242	.021
Sexual Esteem	-.09	-.070	.602
Sexual Distress	-.081	-.345	.003
Sexual Function	.042	.126	.283
Sexual Schema	.042	.126	.283
F = 3.974, p = .003			
R ² = .201			

Table 4.10

Controlling for age at diagnosis on Positive Perception of Cancer on QOL

IOC – Positive	B	Beta	Sig
Constant	16.988		.000
Age at Diagnosis	-.099	-.244	.023
Sexual Esteem	.050	.246	.079
Sexual Distress	-.007	-.039	.738
Sexual Function	-.003	-.135	.269
Sexual Schema	.005	.052	.656
F = 2.403, p = .044			
R ² = .128			

Table 4.11

Negative Perception of Cancer on QOL (no control variables)

IOC – Negative	B	Beta	Sig
Constant	14.333		.000
Sexual Esteem	-.019	-.064	.624
Sexual Distress	.079	.319	.005
Sexual Function	-.048	-.135	.243
Sexual Schema	-.013	-.089	.423
F = 5.253, p = .001			
R ² = .202			

Table 4.12

Psychological Distress (no control variables)

BSI	B	Beta	Sig
Constant	1.174		.000
Sexual Esteem	.007	.156	.239
Sexual Distress	.014	.339	.003
Sexual Function	-.013	-.226	.054
Sexual Schema	-.004	-.162	.147
F = 4.944, p = .001			
R ² = .192			

Qualitative data analysis.

This study explored the ways in which the sexual self themes were reflected in the narratives of eight young adult cancer survivors during a focus group and examined how their responses positively or negatively supported and/or enhanced the quantitative data gathered. Since the transcript was reasonably short from the two-hour interview, the researcher utilized a modified content analysis of the primary themes while coding at the most general level. The qualitative question was: *What was the young adult's experience of cancer and how did it affect his/her sexual self?* Using a structured, open-ended interview guide (Appendix D) and content analysis, the researcher used the following questions to guide the identification of the key themes:

1. What themes emerged from the focus group that supported or challenged the quantitative data?
2. What themes supported the theoretical framework of the study?
3. What new information was revealed about the experience of a young adult cancer survivor?

Description of focus group participants.

Participants in the focus group included three women and five men initially diagnosed with cancer between two and five years before data was collected. Four of the participants had more than one cancer diagnosis. Of these four, two of the men were diagnosed with two different cancers upon initial diagnosis and two of the women had various recurrences or secondary cancers. Seven of the participants were considered to be in remission. However, of these seven one of the women reported she expected for the cancer to “show up again” (S2).

One of the men had stage four cancer. Cancers varied and included thyroid cancers, blood cancers, sarcomas, breast, and lung cancer. The mean current age of participants was 30 with a mean age at diagnosis of 27. Four of the male participants were either married or identified being in a committed partnership, one reported he was single and dating. Of the three women, one was in a significant partnership and the others were single and dating. Sexual orientation varied only slightly with one participant identifying as homosexual and all others as heterosexual. In the discussion that follows, the words of the eight participants are identified by an anonymously assigned subject number for each participant.

Key themes.

There were six key themes that emerged from the qualitative data analysis, which was guided by consideration of the three questions listed above. These key themes, listed below, will be discussed in detail.

Theme 1. Late effects of treatment continue to interfere with the sexual self.

Theme 2. Physical limitations trigger mental limitations that influence the sexual self.

Theme 3. Perceptions of past sexual self influence perceptions of present sexual self.

Theme 4. Communication with partners influences perceptions of sexual self.

Theme 5. Medical procedures negatively influence intimate touch.

Theme 6. Insensitivity of health care professionals to sexual issues highlights the importance of better communication.

Theme 1: Late effects of treatment continue to interfere with the sexual self.

Young adults with cancer often have to go through intensive treatment protocols including surgery, chemotherapy, radiation and/or other treatment modalities. At diagnosis

and throughout treatment, all but one of the participants identified as not having much desire for sexual intimacy with themselves or with their partner(s). “I was trying to gain weight back and, you know, growing hair back and all that stuff. So, I don’t think we really had any feelings like that” (S4). In other words, just regaining strength and some form of normalcy again was the first priority for all. However, many of these young adults have late effects that continue to require ongoing treatment or interfere with resuming what was once their ‘normal’. As one person said, “Cancer introduced real physical limitation” (S1). Late effects can interfere with not only day to day physical needs but also with sexual desires and abilities. Another young man commented that

Because of the medications or just the side effects of my treatment, I’m either not always in the mood or certain sexual acts or intimacy acts that used to be more common for me are either harder for me or just don’t arise as much. (S4)

The influence of these physical changes appeared to heighten the distress and discouragement some of the survivors felt. They reported that unless there is a lot of understanding between partners, “it’s mostly like a failure and it makes it even harder to start the next time” because “you feel like, what’s the point?” (S1).

Late effects can directly and indirectly affect sexual functioning. A young man with chronic graft-versus-host disease who has had physical limitations and felt as though “just trying to bend in certain positions sometimes is impossible or my skin feels like it’s going to rip” (S1). He also stated that he had cardiac issues that interfered with his ability to “last long” (S1) during sexual play with his partner. Many young women are put into a temporary or

permanent menopausal state, after chemotherapy or surgical removal of the ovaries, which can directly affect aspects of sexual functioning. A young woman reported:

There was a time there when I was on chemo and I didn't have hair and had all these scars and, you know, I was a little dry down there. And so, I didn't feel very feminine and that was a little hard. I felt sort of a like 55-year-old woman (S2).

Late effects are often monitored or treated by healthcare providers, but the sexual implications may go unaddressed by the survivor and their health care provider(s). Many of the young adults identified that upon diagnosis the health care providers had to "figure out what they could do to save my life rather than thinking about all the repercussions, including sexual repercussions or financial job repercussions of not having the limb" (S8). When treatment was completed, the focus for many of the young adults was on managing the late effects and neither they, nor their providers may have realized what a toll these effects were taking on the sexual self.

They [health care providers]– no, they don't [address the late effects]– that hasn't at all been touched by or discussed by the doctors and even myself. Actually, I didn't raise that specific problem. I mean, I have been discussing saying, you know, 'I have problems with my sex life.' But, you know what? It actually seems to me so obvious that my physical limitation is a factor to sex performance I guess that... you know, I guess that's why I never ask because it's like, obviously I can't, you know, do this or do that. (S1)

Many of the young adults reported they were still, years later, trying to manage the physical ramifications of cancer and its treatments and to incorporate these challenges into their

sexual self. Challenges varied from learning how to manage the loss of a breast or a leg and wearing a prosthetic to managing the direct physical limitations that graft versus host disease can bring. All of these physical changes and challenges were reported to affect how the survivor viewed his/her sexual self.

Theme 2: Physical limitations trigger mental limitations that influence the sexual self.

Physical changes that limit physical abilities, sexual behavior and function can lead to an increase in sexual distress and introduce “mental limitations” (S1). Although desire for sexual intimacy may return the young adult’s physical limitations, such as joint pain, movement limitations and cardiovascular changes “just makes it that much harder to actually engage [in sex]” (S1). When experiencing high sexual distress and low sexual esteem, young adults may feel stuck in a cycle as they try to improve their sexual function while their sexual distress is still high due to their lower sexual function.

I totally know about that cycle about the physical discomfort affecting my mental state especially when entering a new sexual relationship with somebody that I wasn’t already comfortable with. And then, of course, once the emotions get into it, that makes the – that affects the physical part of it. So, it was like a cycle where, you know, I – it was really something that was difficult to get over. (S6)

Some of the physical effects of cancer, such as fertility loss, may not be a visible scar or physical challenge but add to “emotional scars” (S2) that can be just as challenging to overcome and can change the sexual self. However, it is sometimes the less visible (e.g., reconstruction or fertility loss) or the smaller visible scars (port scars or surgical scars) that can seem to be more distressing to the individual’s sexual self. Although the scars may not

bother the partner and are able to be covered up, physical and emotional scars can lower sexual esteem and increase sexual distress. To address this concern, one woman said: “When I’m intimate – I guess, now that I think of it, I’m kind of more of a ‘lights off’ kind of person” (S2).

Hormone changes in young male and female survivors can have a tremendous impact on not only sexual function, but also the sexual esteem and sexual distress of the survivor. One male (S6) reported that he had experienced a significant change in his testosterone level. Because of lower testosterone he noticed a significant change in his sexual desire stating, “I would have been just as happy to watch a movie” than to engage in sexual play, which bothered him at the time. However, he felt as though the medical team responded to his concern as if he would “just get over it” (S6) and they did not offer him any solutions, which increased his sexual distress until it resolved on its own.

When young women are put into a medical menopause or premature ovarian failure, many sexual changes occur. Two of the young women identified that they had been put into an early menopause and therefore experienced changes in vaginal dryness and changes in libido. Although hormones or the birth control pill were prescribed to help stave off some of these effects for one of the young women, the other was not able to take a hormone supplement, as it would negatively interact with her cancer.

Although the physical changes appeared to create some uncertainty and have the possibility of lowering sexual esteem and increasing sexual distress, young adult survivors also identified that sexual and psychological distress were increased by how their physical and sexual limitations affected their partners. Throughout the focus group, when asked about how

cancer had changed their sexual lives, several participants named feelings of guilt for their partner having to experience all the sexual and non-sexual changes that cancer brought. One participant reported that he did not feel guilt about his lack of desire to have sex with his partner, but rather, felt guilty that his partner also had to adjust to the consequences of his disease. In addition to his life having to “stop and shift gears...hers did too...and she was willing to do so” (S4). This guilt did seem to be woven into the guilt around the physical and sexual changes that the survivors faced due to the treatments. Sex “really wasn’t on my mind” (S4), and for many, the desire to be sexually intimate took a while to return. For some, it has never fully returned. This new reality of change or the survivor’s ‘new normal’ seemed to take on a different meaning for the men who were partnered during their cancer experience. However, one woman reflected:

My need for sex was replaced by – with a need for just touch in general, just any kind of touch like hugs and foot rubs and, things like that because I think the cancer is just so isolating. And so, although I didn’t feel like I had a raging sexual self [before cancer], I definitely craved that different kind of intimacy. (S2)

The men who were partnered at diagnosis tended to identify higher psychological distress around their sexual changes that evolved from their cancer experience. “It’s kind of, you know, the guilt that, they’ve stuck through this with you. So, you kind of feel like you owe them” (S4). In addition to feelings of guilt around the physical limitations that made sex nearly impossible, many reported that sex and sexual intimacy remained important to their partner throughout and after their diagnosis and this added “burden...in...satisfying the partner...is another stress I kind of don’t need right now” (S1). Some of the male participants

reported that their partners had a hard time with their lack of desire or ability to have sex and did not feel as though their partners were able to understand that physical and sexual limitations were not reflective of a desire to be intimate. “I mean sometimes I get a comment that really hurts me as if, like... ‘If this doesn’t improve, I don’t know what I am going to do with you’” (S1). In summary, the young adult’s new physical limitations, due to the diagnosis or treatment of cancer, can have a negative impact on how a young adult views his/her sexual self. Additionally, these physical limitations may add stress to sexual relationships.

Theme 3: Perceptions of past sexual self influence perceptions of present sexual self.

Young adults have amazing resilience and strength. If a young adult had faced challenges prior to cancer that forced them to reevaluate or redefine their sexual self, it seemed easier to adjust to the new changes cancer brought. One young adult expressed candidly how through a diagnosis of HIV four years prior to his cancer diagnosis, he has been able to find his way in the world of dating and redefine his sexual self with the new added limitations. He reported that when he was diagnosed with cancer, he had already dealt with “a lot of body issues, mental issues, feeling like I was broken, damaged goods” (S8). After thinking as though he had successfully made his way through the HIV diagnosis, he was diagnosed with two cancers, but one that required a leg amputation which “threw a new twist in there for me” (S8). In the immediate aftermath of the diagnosis, he spent time exploring the best ways to disclose his cancer and the prosthetic limb when interested in someone and reported:

I get along pretty well with the prosthetic leg now at this point. So, most people wouldn’t know until the clothes come off. But it’s still, you know, are they going to

feel deceived if we've met and talked and they got to like me and then they hear this information? Is it going to feel more deceptive that I let them like me or is it better to get it out there upfront? So, for me I've found that it's better to disclose all that shit; the HIV, the cancer, the amputation, the – you know, whatever it is, get it out there and weed people out. And I find that I still am able to find people to have sex with or date despite those disclosures. (S8)

Many of the young adults discussed how their negative thoughts about themselves, specifically their sexual self prior to cancer, were often exacerbated by the diagnosis and subsequent treatments. For example, two of the men described themselves as “shy” before cancer. Although they had “gotten over it” (S8), the cancer diagnosis brought back many of the insecurities. “It felt like less than square one,” and “it was like I had to work my way back up just to get to square one” (S6). Trying to make sense of thoughts of being “broken” or moving “down a peg from the potential catch I could be to a mate” (S8), while facing normal age appropriate tasks like dating, posed additional challenges to the sexual self. In a society where illness or disability are often viewed as “weaknesses or less desirable traits...a potential mate would be looking for” (S8), the cancer seemed to create greater anxiety in the young adults who were dating or thinking about dating. One participant echoed the anxiety of many of the participants that were single, stating: “I have found that whether it's sexually or even just emotionally that I find that it just seems harder in general to open up to people or to let them in” (S6). Another participant reflected on how she thought she was going to die from her cancer and therefore engaged in two sexual relationships that “were not anything really” and had “regret” about these decisions, stating:

It's painful to be reminded of how I felt before and now I've really realized that I'm going to have a life. I have one. I'm not going to stop everything just because of my diagnosis. I can't. And now I'm, you know, looking for something [a relationship] that's more serious. (S4)

The anxiety reported by the single (and some of the partnered) participants was not about the fear of commitment, but rather about learning to allow themselves to become vulnerable in a relationship after feeling so uncomfortable with the vulnerability they felt during cancer.

Evaluating one's desirability, sexual ability, and what one can offer to a relationship was an important aspect of strengthening the sexual esteem, decreasing the distress, and improving sexual function and behavior for these young adults.

The use of humor, for many, around the new physical limitations or changes appeared to help strengthen sexual esteem and decrease the sexual distress. One young man reported he initially really struggled with his testicle implant not only because he had a lot of discomfort and pain, but also because of his new body-image, with disproportionate testicles. However, when he is facing the possibility of being sexually intimate with someone new, he now discloses the physical changes by saying, "Guess which one is the fake?" (S6). Another young woman reported that she viewed her scars on her neck with pride and viewed them as "battle scars" (S5). If her friends had a hard time looking at the scars she stated she would jokingly tell them "Well, don't look at me, then" (S5). Her ability to incorporate her scars as something that was not negative, appeared to help her sexual esteem. In addition to humor, young adults who demonstrated the qualities of having a higher sexual esteem and lower sexual distress found creative ways to address these changes and hoped for a better or

improved sexual self. “Trying to find something out, like something that will allow me to, you know, be satisfied with, you know, new ways, different things to try” (S1) could strengthen a more positive sexual self by providing opportunity and possibility for improvement.

Theme 4: Communication with partners influences perceptions of sexual self.

Communication with partners about sexual needs can have a positive or negative impact on the various domains of a young adult’s sexual self. Discussing the changes in sexual function or sexual limitations and intimate needs was important to many of the survivors. Several participants reported having conversations with their partners about the new sexual limitations (e.g., “There are certain positions that are less comfortable that I can’t do either, period, or for the same amount of time” (S8)) and emphasized that the limitations were not a direct reflection of their lack of attraction or desire for their partner. “If I don’t have an erection right now or I didn’t orgasm,” that does not mean “I’m not really enjoying this...it doesn’t mean I’ve fallen out of love with you” (S8). These conversations not only allowed the young adults to identify and discuss “what our goals are, what [are] the goals of being intimate together” (S8), but also seemed to decrease the distress and improve the young adult’s sexual behavior. Sexual distress and behavior seemed to be improved through clearly identified expectations for each partner. The conversations allowed for adaptations so they were “both getting pleasure from it” even without the act of intercourse “...[as] there are other things that are equally as valuable to me about being intimate” (S8). Communication helped one woman feel as though her sexual intimacy with her partner was stronger after cancer, with or without sex.

I had two separate oophorectomies [surgical removal of the ovary] and so I was feeling quite a bit of pain even when it was supposed to be okay to have intercourse. And so, initially he [her partner] took that as sort of a rejection because I just didn't want to go there ever. And I think once it was clear that I just – I needed some time, it got better. And so throughout my chemo, and I'm sure a lot of people can relate to this, I didn't want to and shouldn't have anyway because I kept getting infections. So, I think we weathered that okay. (S2)

She later reported that because they were in a relationship before cancer and he knew her history, she felt sexually safe with him, in spite of struggling with her own body image and sexual esteem. At times “he was just incredible...and accepting” (S2). Her partner was “so accepting” and “wanted me to take off my wig all the time even though I didn't want to, and didn't care about my scars” (S2), which helped improve how she thought about herself and “made the big difference” (S2).

Theme 5: Medical procedures negatively influence intimate touch.

Another theme that arose from the focus group was the concept of “safe touch” (S3) and how poking and prodding decreased sexual esteem and increased distress when participants viewed themselves like objects and less like a sexual being. The number of medical appointments and procedures that many of these young adults must face appeared to affect the ways in which they perceived touch. Although well intentioned and for good purposes, blood draws, scans and examinations begin to take a toll on a young adult's sense of that “safe touch” (S3) and for some, this seemed to interfere with wanting to be touched at all. One participant said:

When the doctors poke and prod you - that's really an actually intimate thing to be doing with somebody who you don't know, have no relationship with, but you're developing this kind of crazy relationship with this person who has a lot of control over what they're going to be doing to you, either cutting you up or, you know, going to look at you. And I think that that has affected my sexual intimacy in a lot of ways in that I kind of don't trust people, you know. (S7)

Another young adult reported that he longed to return home from the hospital and have intimate and "safe touch" from his wife and for

...Five minutes just pretend I don't have cancer...and just for a few minutes I knew she [my wife] was there. If a doctor, an oncologist, somebody who wanted to pick me, prod me, poke me, question me or draw blood from me, it was just kind of like 'Okay, you can deal with them. I just need this intimate touch right now. (S3)

A cancer diagnosis can be a traumatic event and its treatment can be an assault to the sexual self, leading a young adult to think "it's harder for me to trust it [intimate touch] in the way I used to now that I've had these horrible things being pushed into me through that same sort of way" (S7). In addition, the treatments and medical care required is perceived by some young adults as invasive and distressing to their current and future relationships as they begin to associate all touch with medical procedures and touch.

Theme 6: Insensitivity of health care professionals to sexual issues highlights the importance of better communication.

The majority of the young adults reported that fertility was approached, but very little else about sexuality was discussed by their oncology team. This was true in the quantitative

survey data collected as well. Most of the young adults reported that if sexual implications of treatment had been addressed, they were the ones to initiate the conversation or the health care team “wouldn’t have brought it up unless I had asked” (S7).

All of the young women in the focus group reported that some information was provided on fertility risks, but they were left to explore many of the fertility sparing options on their own, and they felt discouraged from exploring those options that may have delayed treatment. In both cases where the female’s fertility was affected, they were referred to a fertility specialist after they had completed initial treatments and were diagnosed with a recurrence or secondary cancer. However, they were told it was too late to preserve their own eggs, ovaries, or ovarian tissue. One young woman had reported that she had delayed investigating fertility procedures because it had been presented to her as something she could do ‘in case’ she had a recurrence and had to have treatment again. However, she did not want to “go through the motions of preserving my fertility because it MIGHT come back” (S2). After having a recurrence which required her second ovary to be removed, she was told she could “get an egg donor ... adopt, but that was pretty much it” (S2). The lack of options and/or information provided was interpreted by the young women as dismissive of their needs. “I wish in retrospect I had done something more. And I also wish that my oncologist had, you know, given me more information about all of this” (S2). One young man who has a stage four cancer recalled bringing up the question of fertility with his oncologist:

I had to initiate the conversation with my doctor myself...because I knew nobody who had cancer. As far as at that point in my life, I was the only one in the world that had cancer. And when I brought it up to my doctor...I said, “How long will I be sterile for

due to chemo?” And she looked at me point-blank like I was an idiot...and this was the largest discussion that we had about it. She looked right at me and said, “You probably won’t be around long enough to raise kids. Median life expectancy for Stage IV lung cancer is ten months.” And that was the biggest conversation we had about it. (S3)

Although all reported understanding the urgency to begin treatment, and appreciated that the focus of treatment was to save their lives, the young adults reported feeling frustrated that their medical teams were not more informative regarding how the consequences of treatment might affect their sexuality. Several of the young adults approached their medical team about their concerns regarding the changes in their body images and once again felt their concerns were dismissed. Participant S7 reported to his physician the pain and discomfort he was experiencing, the concerns he had over the unequal size of his testicles, and his diminished libido and weak erections. His surgeon simply replied, “Well it feels fine to me.”

And I was like, “well, thank you. I don’t know if you’ve noticed, but these are not your balls we’re talking about,” you know...And then later when I expressed concerns about, you know, impotency, things like that, he said, “You know, it’s probably all in your head.” And I said, “Well, you know, great. But I still have this problem.” So, he almost kind of wrote me a trial prescription for Cialis just, you know, while rolling his eyes. (S7)

One of the young women (S6) had received radiation to her mantle (chest) as a teenager for a previous cancer, limiting her options for breast reconstruction after her breast cancer diagnosis over two years ago. Participant S6 reported she felt dismissed by her surgeon when

she inquired about her options for reconstruction. “He didn’t really kind of give me that respect and said, ‘No, that’s not an option for you. You can’t have that’ and kind of left it at that. And I responded with saying, ‘Really? Come on. Give me some more options. I can’t just talk to somebody else about this’” (S6). Neither of these young adults felt as though their medical team initially validated their desires to improve how they felt about themselves as sexual beings. Nor did they experience any sense of empathy in the physician’s response.

“Everything that I’ve had to find out as far as ways to cope, I’ve had to talk with other individuals about” (S3). The lack of communication, support resources, or validation regarding long term concerns of body image, sexual function and fertility appeared to lead to feelings of isolation and a lack of trust in some of the medical team members. This is an unfortunate consequence, as young adult survivors are already a challenge to follow due to their transient nature. Only one of the eight young adult participants received information from a provider that validated and normalized some of the physical and emotional changes that can impact sexuality during and after a cancer diagnosis. He reported that he remembered one of his oncology providers stated, “You’ll probably feel, you know, as a result of your treatment, you know, both physically and mentally that – you know, you won’t feel like doing much. It [sex drive and energy] will come back” (S1).

Summary of qualitative findings.

“...People who are in treatment, they kind of don’t prioritize it [sex] right now because they have so much shit to go through anyway it’s kind of at the bottom of the list, something to get to later” (S1). However, when that “later” arrives, the young adult is faced with late effects and physical changes that may interfere with improving sexual function, may

decrease sexual esteem and may increase sexual distress. And yet young adult survivors can identify being able to break the “cycle” of a negative sexual self (at least at times). Survivors can understand their physical and sexual limitations, communicate these changes, use humor, increase intimacy, and develop a trusting relationship with their oncology team. Those who are partnered during their cancer experience may identify higher psychological and sexual distress around not being able to meet the perceived sexual needs of their partner. (Of interest, it appeared in this focus group that the men had higher psychological and sexual distress around their relationships). The responses of the survivors indicate that their sexual needs and awareness of the intimate nature of their roles are dismissed by many of the health care providers. This dismissal leads to a decrease in trust, an increase in sexual distress, and feeling isolated from the health care team. It might be concluded that young adult survivors would experience less psychological and sexual distress if the health care providers gave them information on the sexual ramifications of treatment at the beginning, middle, end and follow-up phases of treatment as survivors’ needs change. The three domains of the sexual self (sexual esteem, sexual affect, sexual behavior) all appear to be important aspects of a young overall adult’s quality of life.

Additional findings.

After further studying of the topic and exploring the data, further multiple regressions and path analyses were run to determine whether it could be demonstrated that indeed, cancer is an event that makes the sexual self in cancer survivors different and different than that of their peers.

Multiple regression.

When controlling for age in healthy peers, none of the models determined significant predictors of quality of life and psychological distress. Additionally, even without control variables, the domains of the sexual self in the healthy peers remained non-significant predictors of quality of life and psychological distress. However, when controlling for age in young adult cancer survivors, domains of the sexual self were significant predictors of psychological distress and overall quality of life. Important to note is that these results are different than when controlling for age at diagnosis, which was not significant with psychological distress.

Controlling for age, sexual distress was predictive of overall quality of life measured by the SF-36 ($F = 3.990, p < .004$). The older the young adult and the less sexual distress the higher the quality of life. Sexual distress was stronger in predicting ($\beta = -.334$) than age ($\beta = .243$). Age and sexual distress explain 20.2% of the variance in the SF-36.

Controlling for age ($p < .06$), sexual distress ($p < .006$) was a significant predictor and sexual function ($p < .06$) was trending toward significant in predicting psychological distress as measured by the BSI ($F = 4.828, p = .001$). The younger the young adult, the lower the sexual function, the higher the sexual distress, and the higher the psychological distress. Sexual distress was the stronger predictor ($\beta = .315$) over sexual function ($\beta = -.226$) and age ($\beta = -.191$). Age, sexual distress, and sexual function explain 22.7% of the variance.

Table 4.13

Controlling for Age on Overall QOL in Young Adult Cancer Survivors

SF-36	B	Beta	Sig
Constant	42.090		.000
Age	.135	.243	.020
Sexual Esteem	-.016	-.056	.674
Sexual Distress	-.078	-.334	.004
Sexual Function	.037	.109	.351
Sexual Schema	.005	.035	.756
F = 3.990, p = .003			
R ² = .202			

Table 4.14

Controlling for Age on Psychological Distress in Young Adult Cancer Survivors

BSI	B	Beta	Sig
Constant	1.768		.000
Age	-.019	-.191	.057
Sexual Esteem	.005	-.112	.395
Sexual Distress	.013	.315	.005
Sexual Function	-.013	-.226	.051
Sexual Schema	.003	-.133	.230
F = 4.828, p = .001			
R ² = .227			

Therefore, this data appears to support that cancer may create an event that makes the young adult's sexual self different than their peers, and these differences affect their quality of life and increase levels of psychological distress.

Path analysis.

Path analysis was an additional method used to explore whether sexual esteem is the mediator of the sexual self. In other words, based on the findings and further exploration of the data, it was hypothesized that a young adult could have low or high sexual function, high sexual esteem, and low distress, which then may lead to either improved sexual function or behaviors. Therefore, a positive sexual self may look two ways: high on sexual esteem, low on sexual distress and low on sexual function, high on sexual esteem, low on sexual distress and high on sexual function. In order to experience low sexual distress, a young adult must have high sexual esteem. In spite of cancer causing challenges around sexual function, with high sexual esteem, low sexual distress and improved sexual function or behavior the young adult's quality of life and psychological distress may also be improved.

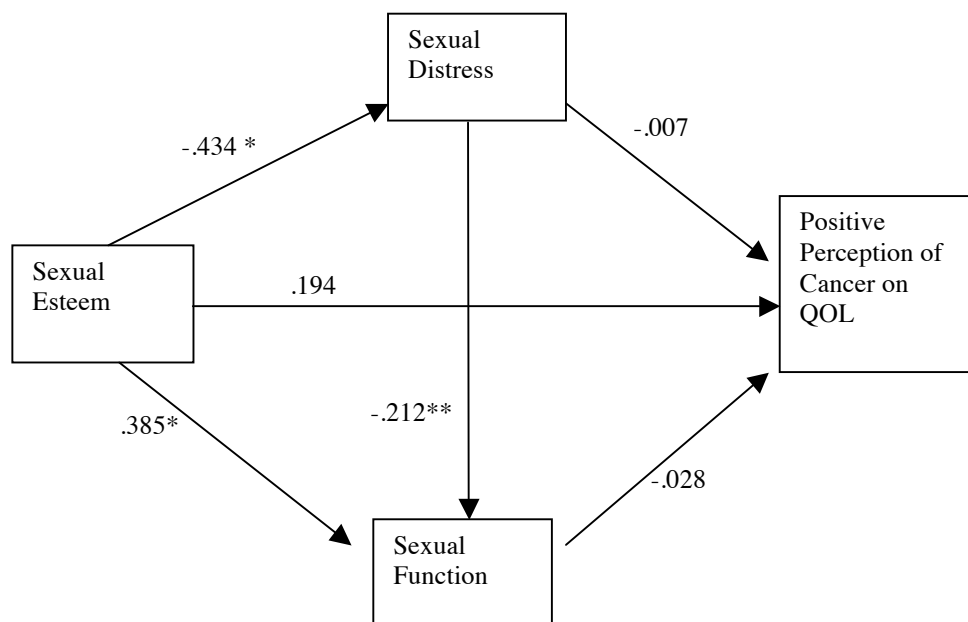
Path analysis seeks to explain variables that may have a statistically significant indirect effect in addition to identifying those with statistically significant direct effects. The variables with indirect effects are intervening variables. The directions of relationships between the variables are shown through pathway arrows which end pointing toward the response variable (e.g., quality of life) and away from the explanatory variable (e.g., sexual esteem). As the sexual self schema scales continued to be non-significant in any of the findings, the researcher began the path with sexual esteem (sexual esteem scale) to sexual

distress (SDS) to sexual function (SFI) and ended at the quality of life measure for survivors (IOC positive and negative scales).

The path diagrams and path coefficients are presented in Tables 4.15 to 4.16. The path diagrams show both the direct and indirect effects of the variables that were statistically significant in the impact on positive and negative perceptions of quality of life (IOC).

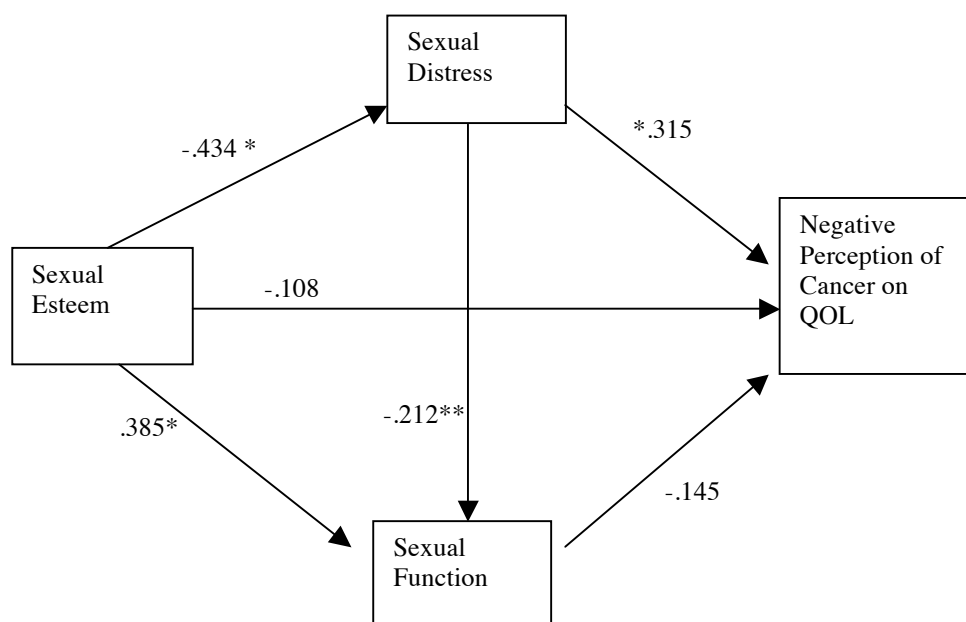
Table 4.15

Path analysis of sexual esteem on positive perceptions of quality of life through the Impact of Cancer Positive Subscale



* $p < .001$ ** $p < .05$

Table 4.16: *Path analysis of sexual esteem on negative perceptions of quality of life through the Impact of Cancer Negative Subscale*



* $p < .001$ ** $p < .05$

The path that included looking at the effect sexual esteem can have on sexual distress, sexual distress on sexual function, and sexual function on perceived positive quality of life, was supported. The path demonstrates that there is a direct effect of sexual esteem on sexual distress, the lower the esteem, the higher the sexual distress. A direct effect of sexual esteem on sexual function is also identified, where lower esteem may directly influence lower sexual function. In addition, higher sexual distress directly reduced the level of sexual function. Therefore, sexual esteem had an indirect effect on sexual function through sexual distress. When a survivor's sexual esteem was low, sexual distress was high, and sexual function was low. As would be expected, none of these variables have a direct effect on the positive

perception of quality of life. A positive quality of life may not be perceived if a young adult survivor has low sexual esteem.

The path that included looking at the effect sexual esteem can have on sexual distress, sexual distress on sexual function, and sexual function on perceived negative quality of life, was supported. The path demonstrated that there was a direct effect of sexual esteem on sexual distress. The lower the sexual esteem, the higher the sexual distress. Sexual esteem also had a direct effect on sexual function. The lower the sexual esteem, the lower the sexual function. Sexual esteem had an indirect effect on sexual function through sexual distress. The lower the sexual esteem, the higher the sexual distress, the lower the sexual functioning. Sexual distress had a direct effect on the perceived negative impact of cancer. Sexual esteem had an indirect effect on negatively perceived quality of life through sexual distress. Therefore, this path (Table 4.16) supports the hypothesis that a negative sexual self (low sexual esteem, high sexual distress, and low sexual function) could negatively influence perceived quality of life. Young adults, who identified lower sexual esteem, higher sexual distress, and lower sexual function, demonstrated a more negative perception of the impact of cancer on their life.

Summary of findings.

The findings of this study indicate that although young adult cancer survivors and their healthy peers may share similar sociodemographic characteristics, the sexual self of a young adult cancer survivor is different than the sexual self of healthy peers. Interestingly, age and age at diagnosis did not seem to have significant effect on most of the dependent variables. However, age at diagnosis was significantly related to sexual distress and overall quality of

life (SF-36), as the older the survivor and the less sexual distress experienced, the higher the quality of life.

Hypotheses one and two remained partially supported. Young adult cancer survivors demonstrated more negative sexual selves with lower sexual esteem, higher sexual distress, and lower sexual functioning. Survivors who identified more aspects of a negative sexual self perception also demonstrated poorer quality of life and higher psychological distress.

Qualitative data enhanced the understanding of how cancer and cancer treatments may influence a change in the sexual self of survivors and the effect this has on their perceived quality of life and distress. The five males in the focus group reported more incidents of sexual distress, which appeared to increase psychological distress. Survivors demonstrated strength, resilience, and creativity to engage in changing thoughts and/or behaviors that improved their sexual esteem, sexual distress, and sexual function and behaviors. The young adults reported that their health care team did not address the topic of sexuality, and this lack of response felt dismissive of their needs. The survivors voiced their desire for the health care team to bring up the topic of sexuality and address sexual concerns on a regular basis.

Survivors who were partnered identified feelings of “guilt” about their partner having to experience the impact of cancer as well, and this was reported to not only affect their sexual distress, but their psychological distress as well. Finally, the young adult survivors appeared to use humor and support resources, such as support groups or online blogs, to improve their sexual self and overall quality of life.

Chapter Summary

This chapter provided the findings and analysis of the two multivariate hypotheses that was tested in this study. The sample population was described through the use of descriptive statistics. Correlations were utilized to examine the relationships between the sexual self of young adult cancer survivors and their healthy peers, the main variables, and the variables included in the multiple regression analyses. Independent t-tests were run to test hypothesis one and multiple regression analyses were run to test hypothesis 2. In addition, additional findings were found upon running more multiple regression analysis on young adult survivors and testing a path model. Chapter Five will summarize all of the presented information, literature and collected data along with a discussion on the implications of research findings on social work and other health care providers' practices.

Chapter Five

Summary and Conclusion

This chapter discusses the purpose of the study, presents an overview of the salient theoretical and empirical literature, and describes the methodology utilized. It will also present and discuss the study's quantitative and qualitative findings and implications for practice. Finally, it will explore the limitations of this study, suggest its contributions to social work and other health care professionals working with cancer survivors, and make recommendations for future research.

Purpose

As quality of life research has strengthened, one area that is beginning to be more recognized is the sexual health needs of cancer survivors (Katz, 2005, 2007; Tan et al., 2003). Young adults diagnosed with cancer between the ages of 18 to 40 are at risk for facing numerous factors that affect their sexual health, both during treatment and long after treatment has concluded (Bolte & Zebrack, 2008). Although the literature has greatly improved in both the areas of psychosocial and quality of life assessments including sexual health, most of the research has looked at childhood cancer survivors or adult cancer survivors, with less known about young adult survivors diagnosed between the ages of 15 – 40. In addition, research on sexual health has primarily examined sexual function, fertility, and/or body image (Katz, 2005; Lee et al., 2006; McInnes, 2003; Schover, 2008), and has not focused, as much, on exploring how cancer may affect broader issues related to sexuality.

The purpose of the quantitative portion of this study was to generate new knowledge regarding the experience of young adult cancer survivors and the difference between their sexual self and the sexual self of their healthy peers. Through the application of Berlin's

(2002) cognitive-integrative conceptual framework, this study sought to develop the concept of the sexual self. Additionally, it was intended to test the possible ways the experience of cancer may impinge on the sexual self of young adult cancer survivors. Furthermore, it was intended to explore whether there was a possible relationship between the cancer-affected sexual self on psychological distress and quality of life in these young adults. The aim of the qualitative portion of the study was to include the perspectives of a small number of the young adult survivors to enrich the understanding of how cancer affects the various domains of the sexual self, and how they perceive the effects on quality of life.

Overview of the Literature

The young adult cancer survivor and sexuality.

Approximately 11.4 million people in the United States are cancer survivors (persons living with or previously diagnosed with cancer) (American Cancer Society [ACS], 2007; Center for Disease Control [CDC], 2009). It is estimated that nearly 70,000 young adults will be diagnosed with cancer every year, with death rates higher than those of their younger and older patient counterparts, and quality of life issues, including sexuality, being significantly impacted (Lance Armstrong Foundation Young Adult Alliance [LAF, YAA], 2008). Of these survivors and depending on the diagnosis, 10% to 100% will experience some form of sexual dysfunction (Beckham & Godding, 1990; Derogatis & Kourlesis, 1981; Ofman & Auchincloss, 1992). According to Curtiss and Haylock (2006):

Cancer survivors often experience long term changes and obstacles, such as impaired immune response, vital organ dysfunction, hormone changes resulting in infertility,

altered sexual function, cognitive changes, ongoing fatigue, depression, anxiety, family distress and economic challenges, to mention only a few. (p. 4)

Sexuality and intimacy are quality of life issues influenced by cancer and its treatments, regardless of age, race, gender, or socioeconomic background (Derogatis, 2000; Katz, 2005; Shell, 2002; Zabora, 2004). Sexual dissatisfaction, whether physical, psychological, or emotional, may not only have an effect on the person being treated for a disease, but also on his or her partner and overall relationships (Svetlik et al., 2005). With young adult survivorship rates on the rise (Adolescent and Young Adult Oncology, Progress Report [AYAO PR], 2006), the sexual self is a critical area to be examined. All of the physical and emotional changes experienced have the possibility of influencing a young adult's perception of self and how she/he gains meaning of her/his world, experiences, and new limitations brought on by the cancer and its treatments.

Common treatments for cancer (e.g., chemotherapy, radiation, and surgery) can have an adverse effect on a person's physiological, emotional, psychological, and sexual well being (Hughes, 2000; Pelusi, 2006; Schover, 1999). This can be experienced in some form of change or interruption to one or several parts of the sexual response cycle, including sexual pain (Andersen, 1985, 1990; Derogatis, 1981; Frumovitz et al., 2005; Lamb, 1995; Lock, 1998; Syrjala, 1998). Hormonal changes, low iron, side effects of chemotherapy and radiation, vascular or nerve damage have also been linked to alterations in sexual function in persons who have or have had cancer (Hughes, 2000; Penson et al., 2000; Schover, 1999). Cancer treatments also heighten areas of distress like pain, fatigue, depression, and anxiety (Zabora et al., 2001), which can also have adverse affects on sexual behavior and function.

Unfortunately, many treatments used to manage the distress of depression, pain, or anxiety also create significant changes in the sexual response cycle, complicating or exacerbating symptoms of sexual dysfunction and how one might view his/her sexuality (Ananth, Jones, King, & Tookman, 2003; Frumovitz et al., 2005; Hughes, 2000; Pelusi, 2006; Spagnola, Zabora, BrintzenhofeSzoc et al., 2001).

Complicating the matter is the ongoing late effects many young adult cancer survivors experience. Late effects can be defined as side effects of treatment that last months to years (some permanent) as a result of the cancer treatments and can include physical and mental health problems as well as secondary cancers (NCI, 2009). The spectrum of late and long-term side effects can range from treatable (e.g., hyperthyroidism) to serious (e.g., infertility or secondary cancers) to lethal (e.g., congestive cardiac failure) (Aziz, 2002). Late effects of radiation and chemotherapy can include cardiovascular problems, and patients may experience inflammation of the heart muscle, congestive heart failure, and heart disease – all of which can impinge upon an individual's physical activity level, including sex. Graft versus host disease (GVHD) occurs when a donated stem cell graft attacks the normal tissue of the person with cancer and can cause skin blisters, jaundice, rashes, and dry skin. Chronic GVHD occurs in 30% of patients who survive at least 100 days after allogenic bone marrow transplant (BMT) and can attack the female genital tract. Endocrine system (hormone) changes are also common results of chemotherapy and radiation in both men and women. Common presentations of sexual dysfunction include loss of sexual desire, difficulty achieving orgasm, pain with intercourse, sexual inactivity and sexual dissatisfaction (Boehmer, Potter, & Bowen, 2009). Infertility for both men and women is a great risk of

having chemotherapy, however, younger survivors, especially men, seem to have a greater chance of recovering their fertility several years post-treatment. Changes in how the thyroid gland works may also occur as a result of treatment, as there can be hormone changes and weight changes. One of the most common complaints of all cancer survivors is long-term fatigue, which can be caused by anemia, pain, a slow thyroid gland, and/or depression (ACS, 2009; Cancer.Net, 2009). As fatigue increases, activity levels decrease, and cardiovascular and respiratory functioning decrease, leading to the loss of physical function and chronic fatigue that may persist for months or even years after treatment (Evans, 2002; Wilmoth, Coleman, Smith, & Davis, 2004), all of which can directly affect the sexual response cycle.

Just as thoughts and interpretations of events affect sexual function, neurobiology is also a critical component of sexual function and important to the explanatory theory of this research. The brain is a major organ whose anatomy and function is regulated by testosterone, estrogen, progesterone, and other hormones associated with the reproductive system. Many different organs and systems are involved in coordinating sexual response including the brain, the spinal cord, blood vessels, the reproductive organs, and various hormones such as testosterone and estrogen. Interference with any one of these factors can result in sexual dysfunction (Crone & Wise, 2004; Plaut, Graziottin, & Heaton, 2004). When examining desire, arousal, and orgasm, there is a complex interaction of the endocrine, nervous, and vascular systems. The biological basis of each of these phases—desire, arousal, and orgasm—is important for health care providers to understand in order to correlate organic issues with functional problems (Crone & Wise, 2004).

Research findings suggest that aspects of the sexual response cycle in survivors often decrease in intensity and frequency after treatment compared to pretreatment status (Syrjala et al., 2000), with the most common complaint by men and women being the decrease in libido (Andersen, 1985; Andersen, 1990; Derogatis, 1981; Frumovitz et al., 2005; Lamb, 1995; Lock, 1998; Syrjala, 1998). Problems with sexual function appear to be multifactorial in cancer survivors (Monga, 1995), influenced by the biophysical and psychological/emotional side effects and late effects of treatments in addition to how a person perceives all of these changes. Monga (2002) reports two variables that influence a cancer survivor's sexual function and view of his/her sexual self: dysfunction and disfigurement. Dysfunction can present itself in various physical and emotional ways (directly related to treatment effects) through effects like fatigue, menopausal symptoms, incontinence, unmanaged pain or pain medication, cognitive, and/or neurological changes. Disfigurement can present as surgical scarring, and visible physical changes such as drooling due to lack of motor/muscle control and weight gain/loss, and can promote poor body image (Monga, 2002). Dysfunction and disfigurement have the possibility of changing a young adult's perception of his self or her self, feelings of loss around changes in his/her social and personal life and how she/he gains meaning of her/his world within the new limitations brought on by cancer and its treatments.

Young adulthood is typically a time of major changes, stress, and exploration that can confound a young adult cancer survivor's developmental experience (Zebrack, 2008). Healthy sexual development is based on "the delicate interplay of physical, psychological, and interpersonal factors. Young adults with chronic illness, including cancer, must tackle normative development issues and treatment-related challenges" (Olivo & Woolverton, 2001,

p. 172). Cancer and its treatments can create challenges to the normative developmental process causing an interruption of identity development, the search for a world view, autonomy, future orientation and interpersonal functioning (Olivo & Woolverton, 2001; Robert, Turney, & Knowles, 1998; Stern & Zevon, 1993; Zebrack, 2008). During the early young adult years, a significant part of self-esteem is derived from sexual identity and, therefore, a cancer diagnosis may challenge a positive sexual identity among young adults (Eccles et al., 1993). There is little written about the older developmental years of a young adult (e.g., 28 – 40), but in this researcher's professional experience, the older young adult may be exploring how to choose to be single, or the changing role of being single to a committed partnership and then having children, may influence the development of the sexual self. Young adults may also be gaining more confidence, "peace" (as one young adult reported to this researcher), or comfort in their sexual identity and/or how they view themselves as a sexual partner and sexual person. Parents and peers may also influence the views and developmental changes in the sexual self of young adults throughout their young adulthood (Evan et al., 2006). In addition to the already challenging ongoing development of the sexual self as a young adult, the treatments for cancer and the late effects add a layer of confusion, frustration, or may complicate sexual and intimate matters, causing the individual to further delay in growth of the sexual self.

Young adult survivors, in general, often have well-developed global self-concepts (Anholt et al., 1993), which of course may vary based upon their age at diagnosis. For example, a 32 year old may have a better developed global self-concept than a 23 year old. However, there have been reports that while they may feel accomplished and adequate in

some areas, they seem to be less confident in their sexual self-concepts (Anholt et al., 1993; Evan, Kaufman, Cook, & Zeltzer, 2006; Fritz & Williams, 1988), and a diagnosis of cancer or other illness may create questions or chaos in their sexual identity. A young adult's view of him/her self may be partly determined by his or her socially defined roles or positions (e.g., partner, star athlete, "smart kid", student, father/mother, employee). When this role or position is lost or significantly changed because of a disease or crisis, the resultant loss creates alienation from peers, which is an essential part of a young adult's identity and development (Hughes, Sharrock, & Martin, 2003). This alienation might also have a negative impact on the sexual self and sexual experiences in which the young adult participates. A diagnosis of a chronic or terminal illness may deprive young adults of being understood by same-age peers who are physically capable, thereby preventing them from participating in normal and age-appropriate activities, including sexual experimentation, sexual activities, and developing or deepening intimacy. All young adults will most likely experience some form of a challenge to their sexual identity and sexual choices, as young adulthood is a "time of increased vulnerability and stress" (Zebrack, 2008, p. 1353). This increased vulnerability and stress could present young adults who face a chronic disease during these years with major milestone challenges above and beyond those faced by their peers (Evan, Cook, Kaufman, & Zeltzer, 2006; Lock, 1998; Zebrack, 2008).

Along with facing a threat on mortality not many of their peers are faced with, new scars from surgery, physical limitations (like breathlessness or limb amputation), permanent hair loss, or other changes, will also need to be incorporated in to one's sense of self (Costanzo, Ryff, & Singer 2009; Evan et al., 2006). For the individual who may still be

struggling with or perhaps is in crisis about who his ‘self’ is, the changes cancer can bring could have significant negative ramifications on his sense of self (Evan et al., 2006). For example, a young adult’s self-esteem may be waning as she thinks “I can’t have children the ‘normal’ way...I will never be normal and no one will ever want me.” However, there is some evidence that an illness may also enhance a person’s sense of self and competence, where the young adult may think “There are lots of people who are infertile...I am not any different from them; I will be able to be a parent of a child who really needs a home and will find a mate who wants to share this with me.” The inability or ability to integrate this information positively into one’s overall identity could influence the development of positive sexual and self esteem (Erikson, 1998; Evan et al, 2006).

Sexual health concerns in the adult oncology population have been identified in several studies (Katz, 2005; Schover et al., 2002, 2003, 2004, 2005; Sundquist & Lee, 2002). “Cancer survivors are at risk for alterations in sexuality and sexual health as a result of changes in physiologic, psychological, and social dimensions of sexuality, and the interactions among these dimensions” (Tierney, 2008, p 72). Some of the challenges surrounding research on cancer and sexuality, is that sexuality, sexual health, sexual self, etc. are not well-defined concepts prior to doing the research. Monga (2002) claims that it is essential that researchers examine and understand sexual behavior, including the act of sexual play with oneself or others, to truly understand the possible influences cancer and its treatment have on sexuality, and goes on to claim this has not been well studied in persons with cancer. This researcher hoped to more clearly define the concept of the sexual self and identify possible

relationships between a cancer diagnosis, the sexual self, and perception of quality of life to inform future research.

Study Variables and Theoretical Support

The sexual self.

Influenced by previous research, the concept of the sexual self, as defined by this researcher for this study, builds upon the concept of sexual self schemata (Andersen & Cyranowski, 1994) to involve a working cyclical interaction of sexual esteem, sexual affect/feelings, and back to sexual function and behavior.

Cognitive theory claims that an individual is an “information-processing organism, one who takes in data (from both outside sources and inside reading) and generates appraisals” (Schuyler, 1991, p. 34). Schemata are memory structures of conceptually related elements that guide the processing of information. Self-schemata are then the cognitive generalizations we create about the self derived from repeated experiences, categorizations, and evaluations of behavior from oneself and others (Berlin, 1996). The data or information gathered are stored in two types of memories, episodic and semantic, in order to be drawn from and to make sense of events. Episodic memory (introspective knowledge about one’s thoughts and perspectives) and semantic memory (general knowledge about concepts, attributes, and language) influence various mental representations about the self and contribute to the knowledge that is drawn from to “make sense out of what they encounter, to identify options for responding, and to experiment with efforts to manifest or do what is desired and to avoid or guard against what is undesirable” (Nurius, 1994, p. 224). As life experiences continue to occur, these memories are stored as schemata in order to organize all

of the events and memory patterns to help us know “what goes with what” and guide our interpretation of events (Berlin, 1994, p. 6). Functions of self schemata are to organize incoming information into an integrated knowledge structure, to help with the retrieval of behavioral instances, to resist inconsistent information and to provide plans for future behaviors or push toward future goals (Markus, 1977). These schemata guide the development of various selves and the information we select about ourselves in various situations (Markus & Nurius, 1986). For example, a young man who is going to a party where he will know few people may retrieve the schema of ‘people person’ with the thoughts “I’m friendly and people generally like me” and therefore, he is able to feel calm and relaxed and perceives the experience as positive.

Repeated similar experiences teach us what to expect, what to do, and how to understand our needs and resources (Berlin, 1996). Individuals impose different interpretive patterns, schemata, on similar events and then construct our own experience of that event. Negative thoughts about the self seem to be the most prevalent thoughts when a person is depressed or experiencing a lower self-evaluation. These negative thoughts appear to generalize all other thoughts about the self and become the lens through which the individual looks. On the contrary, when a person experiences thoughts of competence, these thoughts trigger both positive feelings and positive behaviors that express more confidence (Markus, 1977).

Individuals adapt by searching and constructing meanings that will enhance their sense of security and continuity and serve their goals. The meanings people construct are a

function of their experience-based cognitive systems for understanding and the nature of the information available to them. (Berlin, 1996, p. 326)

Cognitive theorists support the idea that individuals contain many selves and access them when making sense of a particular thought, situation, or event (Berlin, 2003; Markus & Nurius, 1986; Nobre & Gouveia, 2000). As self experiences accumulate and memories mount up, Berlin (2002) states:

Our overall sense of self...becomes more complex...(and) whatever the array of self-relevant sensations, definitions, images, feelings, and actions are active at the moment makes up what is variously referred to as the “working self-concept”...and is the self that is in charge at the moment. (p. 98)

These “working self concepts” or “possible selves” are subsets of self-schemata that represent the hopes and desires we strive for, including our sexual desires (Berlin, 2002).

The concept of the sexual self as developed by this researcher for this study is constructed from a cognitive theory approach. It includes a “cognitive view about sexual aspects of oneself [e.g., desirability, femininity/masculinity, sexual functioning]; it derives from the past experiences and manifests in current experience, and it guides” (Andersen & Cyranowski, 1994, p. 1079). The sexual self, as claimed by Andersen and Cyranowski (1994), is related to intrapersonal and interpersonal aspects of sexuality. However, this model expands on the cognitive concept of sexual self schemata (Andersen & Cyranowski, 1994) to involve a working cyclical interaction of three components: sexual esteem, sexual feelings/affect, and sexual function and behavior.

This cyclical model in young adult cancer survivors includes a fourth component, the event of the experience of cancer as information that must be processed and absorbed into the sexual self. The sexual self, as all selves, can be flexible, cohesive, differentiated, and multifaceted and will gain knowledge and adapt based on experiences in the environment and relationships. However, depending on both the nature of the cancer information and the meaning made of it, there can be a detrimental effect (Berlin, 2002).

The cycle begins for a young adult with the uncontrollable event of a cancer diagnosis providing information that influences, among other things, a young adult's sexual self. Many of the treatments directly affect sexual functioning and this changed functioning is objective information in itself. However, her interpretation of the sexual dysfunction, feelings about sexuality including distress, may further impact sexual functioning in a negative, positive, or neutral way. New information has to be absorbed into the sexual self through the sexual schemata. The sexual self remain stable, or could experience distress according to the meaning assigned to the sexual dysfunction (for example). Very simply, the external events or information that affects sexual function are often ones that are out of the woman's or man's control. Cancer and its treatments can be a direct attack on the young adult's sexual response cycle and ability to experience desire, arousal, and orgasm. One young adult may get this information (sexual dysfunction) and interpret it through a positive sexual esteem ("I'm just as sexy even though my desire for sex has changed"), and experience low distress because of this positive sexual esteem, in spite of the sexual dysfunction. It is the sexual function or physical changes that the young adult would need to make sense of and how they might adapt, adjust, or display maladaptive thoughts towards these changes. Alterations in a person's

sexual self perception negatively affect the quality of life of cancer survivors (Ferrell & Dow, 1997; Hughes, 2000; Katz, 2005; McKee & Schover, 2001; Prieto et al., 1996). A negative sexual self would consist of low sexual esteem, high sexual distress, and low sexual function.

Berlin (2002) reports that people who identify a greater number of self-concepts and relative independence among them can better adapt and withstand the emotional and physical impact that negative life events may create. Negative information (e.g., cancer) can be an assault to the sexual self, as some may interpret the changes that incur as a problem. A positive sexual self may remain intact or not be negatively affected despite information provided by a cancer diagnosis and treatment, and the person would continue to have the hope of possible sexual selves for the future.

Sexual esteem.

The cancer event information enters the cycle and is interpreted by the survivor's sexual esteem. Sexual esteem, or how one thinks about one's sexuality, is formulated as a set of sexual self-schemata (Andersen & Cyranowski, 1994). This sexual self-esteem includes schemata of judgments about oneself in the area of sexuality, values, and cultural influences that have created and influenced how an individual evaluates himself as a sexual being. Our sexual esteem or schemata about our sexuality (e.g., "I am not attractive and will never be," "I am loveable and desirable," or "Being lesbian/gay is not okay") are learned memory patterns (memories established from previous experiences and information that shape and influence the way we interpret current information), and attitudes developed through repeated encounters with similar experiences, perceived good or bad sexual experiences, and/or religious experiences or beliefs.

Negative or positive thoughts that are retrieved from the sexual esteem influence feelings and behaviors (Cyranowski & Andersen, 1998; Nobre, 2003). This would seem to imply that a young adult with a low sexual-esteem, prior to cancer, appears to be at greatest risk for sexual difficulties. She would have more difficulties because she generally is less romantic/passionate in her emotions, less open to sexual experiences, and more likely to have negative feelings about her sexuality (Andersen & Cyranowski, 1994). Thus, in the context of cancer - with disease or treatment factors causing direct changes to the sexual body or sexual responses - we might conclude that young adults with low sexual esteem are at greater risk for sexual difficulties and a negative sexual self-perception.

Sexual affect.

The cycle continues with sexual affect that is influenced by sexual esteem. It may be either positive or negative in the form of distress. Sexual distress is experienced in response to negative thoughts about one's sexual self-worth; how one feels about sexual function or dysfunction; anxiety, depression, excitement, and sexual pleasure that arises from sexual function and dysfunction. Heiman and Rowland (1983) and Beck and Barlow (1986) found that sexually dysfunctional subjects reported significantly more negative affect (e.g., sadness) or thoughts of negativity (e.g., "I am worthless in bed") during erotic exposure. When negative affect in sexually functional individuals has been manipulated, a delay in subjective arousal occurs (Meisler & Carey, 1991), and individuals experience a decrease in firm erections (Mitchell, DiBartolo, Brown, & Barlow, 1998). As a young adult seeks meaning through his/her sexual schemata and sexual esteem after a diagnosis of cancer, the thoughts that arise can create negative or positive feelings. Feelings that might be associated with

sexual esteem include anxiety, fear, sadness, guilt, arousal or “being turned on”, sensuality, and happiness.

Not all young adult cancer survivors identify high distress, even though it is assumed that most will experience decreased fertility and possible decreased sexual function from treatments (Skinner et al., 2007; Zabora et al., 2001; Zebrack, 2004). Although distress and stress are prevalent in survivorship, the stress (or lack of stress) of cancer does not fully explain all sexual outcomes. Young adults may use denial to cope with the changes and distress that cancer has presented. Some may refuse to think about sex at all or say “That should be the last thing on my mind”, “I should just be happy to be alive”. This may also be to dismiss the sexual side effects they are experiencing or not have to acknowledge and work through these effects. “Patients who have been sexually active and functional until an illness often claim afterward to have no further interest in sex. Men are particularly likely to deny all sexual desire when a disease impairs erections. Women seem more vulnerable to illnesses that affect their physical appearance” (Schover, 1999, pg. 72). However, the C-I perspective would explain the difference in distress levels among young adults through the way each makes meaning out of the cancer experience and their sexual self through the retrieval of previous thoughts and experiences from their environment. Individuals who have had negative perceptions of their sexual self prior to cancer may experience an increase in negative thoughts as it relates to their sexuality.

Sexual behavior and function.

The cycle of sexual self culminates in sexual behavior and function. Sexual behavior or sexual function expresses the sexual thoughts and feelings through behaviors like kissing,

having sex, masturbating, putting on makeup, and being intentional about looking nice.

Sexual behaviors may also include negative ones such as isolating oneself from any intimate or physical contact, difficulty with sexual function due to low sexual esteem and high sexual distress, anorgasmia from anxiety about performance or pain, or sexual aversion. Positive sexual behavior that results from a positive sexual esteem and positive affect reflects an overall more positive sexual self.

Sexual dysfunction in the broad sense may be defined as any disruption to sexual interest or activity that results in distress. The inability to engage in a desired sexual activity may be due to physical, psychological, emotional, or biological reasons. Additionally, strained or negative relationships may also affect sexual function. Sexual dysfunction is not a life or death issue, but it is a very real quality of life issue for many cancer survivors and can contribute to stronger feelings of depression, anxiety, or low self-esteem (Evan, Kaufman, Cook, & Zeltzer, 2006; Pendley, Dahlquist, & Dreyer, 1997; Zebrack, Foley, Wittman, & Leonard, 2009). Therefore, satisfactory sexual function among cancer survivors would be the ability to engage in any desired sexual activity. Cancer treatments can directly and indirectly impinge upon sexual function. Any changes in sexual responses, such as decreased libido, are then interpreted, and the meaning of the change within her/his sexual esteem or schemata is incorporated into the sexual self.

To summarize, the cyclical model of a positive sexual self in a young male diagnosed with colon-rectal cancer might be expressed as:

1. Information or Event: A side effect of the cancer treatments, such as a weaker erection, is experienced and cues the information to be interpreted;

2. Sexual Esteem: The external event filtered through the schema of a positive sexual self leads to an interpretation about the weaker erection, such as coming from a schema of competence, “I am competent and can be creative about how to manage this”;
3. Sexual Affect: These thoughts of competence lead to a feeling, such as relaxation and low sexual distress;
4. Sexual Behavior and Function: The thoughts of competence also leads to an increase in desire and may lead him to choose to engage in behaviors that indicate to his partner an interest in being intimate, such as initiating sexual play, or asking for more foreplay; and
5. Strengthens or threatens the sexual self: The cycle continues to repeat itself. If distress is present it will repeat until there is recognition of distress or a positive resolution is found and the thoughts or schemata triggering the negative or positive emotional and behavioral responses are evaluated and changed.

In the situation described above, the young adult is displaying comfort and competence in sexual contact with his partner, affirming his schema of self-competence, and creativity. If he encounters any other sexual difficulties or dysfunctions, he would go through this cycle again and reevaluate that event and its meaning in the same way, possibly retrieving a different schema or sexual esteem that might bring about a different behavior and result.

Quality of life.

Quality of life (QOL) is a term commonly used in research on cancer survivors’ overall well-being and enjoyment of life. Many of the studies that evaluate quality of life in cancer

survivors study “aspects of an individual’s sense of well-being and ability to carry out various activities” (NCI, 2009) in four common domains: physical, psychological, social, and spiritual well-being (Ferrell, 1996). Changes in one aspect of quality of life (e.g., pain) can influence perceptions in other domains (e.g., sexual function) and are best evaluated when defined from the patient’s perspective (Ferrell & Hassey, 1997).

Quality of life is a subjective term and certainly can vary based on a person’s perceived experience and internal and external resources, as well as their diagnosis, treatment protocol, prognosis, etc., however all persons diagnosed with cancer will experience a change in aspects of their quality of life (Rowland, 1990). “The survivorship literature supports [Rowland’s] theoretical assertion that, regardless of the type of cancer, all people diagnosed with cancer experience altered relationships to some extent, dependence-independence issues, achievement disruptions, impact on body and sexual image and integrity, and existential issues” (Zebrack, Yi, Petersen, & Ganz, 2007, p. 891). Limited research exists on the quality of life of young adult cancer survivors, diagnosed as young adults (Roberts et al., 1997; Zebrack et al., 2006; Zeltzer, 2006) and most of the literature reported in this dissertation has been drawn from research focused on young adults who are survivors of childhood cancer.

Zebrack and Chesler (2001) studied cancer-specific and general health worries of 303 childhood cancer survivors (individuals that had been off treatment for any length of time and were 14- 29 years old) and concluded that males reported less cancer-specific and general health worries than females and older survivors reported increased worry about cancer-specific issues than younger survivors. Another study by Mackie, Hill, Kondryn, and McNally (2000) evaluated 102 childhood survivors of acute lymphoblastic leukemia (ALL) and Wilms tumor,

aged 19 – 30, and compared them to 102 healthy non-related peers evaluating psychiatric disorders, intellectual ability, and interpersonal and social-role performance. There was no difference in the rates of psychiatric disorders, but survivors did report significantly poorer functioning in partnered sexual relationships, friendships, non-specific social contacts, and day-to-day coping than their comparison group.

Cancer survivors experience a vast array of negative thoughts and emotions such as the fear of dying, loss of self-efficacy, impaired self-esteem, fear of rejection or abandonment, weight, sleep and appetite disturbances, role changes, etc. which can impact one's interest or desire for sex and enjoyment of intimate relationships (Anllo, 2000; Block, 1997; Razavi & Stiefel, 1994). Alterations in a person's sexual self perception negatively affects the quality of life of a cancer survivor (Ferrell & Dow 1997; Hughes, 2000; Katz, 2005; McKee & Schover, 2001; Prieto et al., 1996). Clearly, sexuality and sexual health are key aspects of a person's perceived quality of life, and therefore, a young adult's quality of life may be improved when their sexual self is more positive. It was this researcher's intention to explore whether there is a relationship or interaction between a negative sexual self and lower quality of life.

Psychological distress.

“Distress is an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with people's ability to cope” (NCCN, 2007, p. DIZ-2). Therefore, psychological distress may be viewed as an aversive reaction to perceived internal and/or external stressors, which lead to actions aimed at addressing, adjusting to, or ignoring stressors (Derogatis & Melisaratos, 1983; Zabora et al., 2001). Although research shows that cancer survivors are likely to experience increased psychological distress following a cancer diagnosis,

distress is not always recognized, addressed, or followed for change by health care professionals (Borval, Maunsell, Brisson, & Masse, 1998; Hoffman & Recklitis, 2009; Zabora et al., 2001; Zebrack et al., 2007). The psychosocial and psychological distress needs of the adolescent and young adult group are specific and differ from those of either children or adults (Ellis, 1991; Mulhall et al., 2004; Ritchie, 2001; Smith, 2004; Society for Adolescent Medicine, 1996). “Off-time”, or non-normative, life events occurring outside the typical age range, such as a cancer diagnosis or a change in expected sexual function in young adult years when typically occurring in older adults, are more likely to be distressing or traumatic to a young adult (Baltes, 1979; Costanzo et al., 2009; Erickson, 1998; Neugarten & Hagestad, 1976).

Persons surviving cancer for at least five years are more likely to show signs of psychological distress than their peers (Hoffman & Recklitis, 2009). Hoffman and Recklitis (2009) evaluated psychological distress in those persons diagnosed with cancer as an adult five years or more post-diagnosis ($n=4,636$) as compared to their peers (persons with no cancer history in same age brackets) ($n=122,220$). They reported that high psychological distress was identified in more than 40% of the survivors that participated in the study in comparison to their matched peers. Understanding and interpreting young adult cancer survivors’ experience of distress is essential, as many factors that increase distress (being uninsured, comorbid conditions or secondary cancers, no spouse or live-in partner, and aged under 45) may be common factors in their lives (Hoffman & Recklitis, 2009; Hudson et al., 2003; Zebrack et al., 2004; Zebrack et al., 2007). Sexual and relationship concerns have been reported to increase psychological distress in cancer survivors (Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Schover, 1994; Schag, Ganz, Ponlinsky, Fred, Hirji, & Petersen, 1993). It was this researcher’s

intention to explore whether there is a relationship or interaction between a negative sexual self and higher psychological distress.

Summary.

In conclusion, there is clearly literature that supports the experience of quality of life, psychological distress, and changes in a cancer survivor's sexual self (sexual function and behavior, sexual esteem, sexual feelings/affect). However, there are clear limitations in the research examining the young adult survivor population. Further research that utilizes both qualitative and quantitative methods is needed to explore not only the experience of cancer on their sexuality, but the direct physiological and psychosocial impact cancer had on sexual functioning. Future research must be designed in such a way as to truly capture the experience and expression of the late effects cancer has on young adults' sexuality and perception of the sexual self.

Methodology

An exploratory cross-sectional survey design utilizing a multi-modal method of data collection was utilized. A multi-modal approach was used for "corroboration as well as completeness" (Padgett, 2008, p. 227) in gathering information that was testable and measurable and enriching the data with the exploration of the young adult's experience of the problem. "The ecological validity of a quantitative study can be enhanced considerably by grounding the study in qualitative interviews and observation before and/or after" the quantitative data is gathered (Padgett, 2008, p. 224). Positioning the focus group after the quantitative information was gathered, supports and enlivens the study's data (Padgett, 2008). The quantitative data was collected through a demographic questionnaire and eight standardized

instruments that measured psychological distress, quality of life, and the various aspects of the sexual self for the young adult survivor and the healthy peer. The young adult cancer survivors were administered a second quality of life scale specific to cancer, titled The Impact of Cancer Scale. Qualitative information was collected on the young adult cancer survivors through a semi-structured telephone focus group.

Population and sample.

The population consisted of 167 young adults aged 18 to 40 from the United States and Canada. The sample consisted of two groups of young adults: 113 cancer survivors who were initially diagnosed with cancer 2 to 5 years ago (allowing for recurrent or metastatic disease) and 54 peers with no history of cancer. Survivor participants were made aware of the study through various national young adult cancer survivor not-for-profit organizations announcing the study on their websites and through e-mail blasts (e.g., Planet Cancer; Young Adult Cancer, Canada; Fertile Hope; The Ulman Fund; I'm Too Young For This). The websites and email blasts contained a description of the research, the researcher, and a link to the study website www.sexualselfandcancer.com. The "I'm Too Young For This" organization had the researcher on their weekly radio show and asked questions about the study, providing the study website to listeners and also on their website. The healthy peers were recruited utilizing a snowball sampling technique, requesting that survivors provide the survey link to two peers with no known history of cancer.

Quantitative portion of the study.

The quantitative portion of the study tested the study's two hypotheses:

H1: Controlling for current age, young adult cancer survivors will identify more negative sexual selves than their healthy peers; that is they will have lower sexual functioning, lower sexual esteem, and higher sexual distress.

H2: Controlling for current age and age at diagnosis, the more negative the sexual self in a young adult survivor, as indicated by lower sexual functioning, lower sexual esteem, and higher sexual distress, the higher the psychological distress and the lower the overall quality of life.

The study's quantitative variables and measurements.

This study utilized seven standardized instruments: sexual self, quality of life, and psychological distress. In addition, all participants were asked to respond to several demographic questions, including age, education, sexual orientation, relationship status, age they became sexually active, if (and at what age) they had ever engaged in non-consensual sex. Survivors were also asked for their age at diagnosis, treatments received, and open-ended questions on information they had received from their health care team on sexual health. The variables and the instruments used to measure them are further described below.

Disease.

Disease was measured through a Yes/No format inquiring whether the young adult responding did or did not have a diagnosis of cancer. Disease was identified as the independent variable in hypothesis 1. Participants identified themselves as either having had a history of cancer, or having no history of cancer as the first question of the survey. Based on the response, the participant was presented the survivor or healthy peer survey.

Sexual self.

The sexual self was conceptually defined as a working interaction of three components: Sexual Function, Sexual Esteem, and Sexual Distress. A negative sexual self would be low on sexual esteem, high on sexual distress, and low on sexual function. The sexual self was the dependent variable in H1 and the independent variable in H2. The sexual self was operationalized by the use of four standardized instruments.

Sexual function.

Sexual function was defined as the ability to successfully engage in sexual activities. A dysfunction was a disturbance to any component of the sexual response cycle (sexual desire, sexual arousal, orgasm, as well as sexual pain) and that was distressing to the person. Sexual function was measured through the use of a modified 19-item questionnaire designed to assess the key dimensions of sexual function (desire, arousal, lubrication, orgasm, satisfaction, and pain) (Rosen et al., 2000; Wiegel et al., 2005). The original scale, Female Sexual Function Inventory (FSFI), was modified, with permission from the authors, to assess both male and female sexual function and was titled in this study The Sexual Function Inventory (SFI). The scale was modified to include males by adding the word erection in the questions that inquired about lubrication. All other questions were gender neutral in their sexual function reference. Each item was scored with a 5- or 6-point Likert scale. The scores varied from 0 to 5 or 1 to 6, depending on the domain. A total score more than one standard deviation below the mean of a normal population (25.2) (as reported by Rosen et al, 2000) was considered “abnormal.” To obtain the overall score, the six domains were added together.

A score of zero in the individual domains indicate the participant reported having no sexual activity in the past month.

Sexual esteem.

Sexual esteem was defined as cognitive appraisals and attitudes toward one's self along with the quality of sexual schemata. Sexual esteem may also be seen as a generalized tendency to positively evaluate one's own capacity to engage in healthy sexual behaviors and to experience one's sexuality in a satisfying and enjoyable way (Snell et al., 2001). Sexual esteem was measured using two scales: 1) the Sexual Esteem Scale (Snell, 2001) and 2) The Sexual Self–Schema Scale (SSSS) for both women and men (Andersen & Cryanowski, 1994; Andersen et al., 1999).

The Sexual Esteem Scale (Snell, 2001) is a 10-item, 5-point Likert subscale of the Sexuality Scale. Answers, which are added together for total score, range from Agree (5) to Disagree (1) where higher scores correspond to greater sexual esteem. With permission from the author, the subscale of Sexual Esteem on the Sexuality Scale was utilized and it has been reported that subscales can be used independently without effecting reliability (Snell, 2001).

It has been reported that men's and women's sexual schema are different and a specific scale for each have been developed (Andersen & Cyranowski, 1994) and were utilized in this study to explore one's self concept as a "sexual person": The Men's Sexual Self Schema Scale and The Sexual Self Schema Scale – Women's Form. The scales (45-items for men and 50-items for women) are comprised of items that do not explicitly refer to sexuality but provide adjectives that can be associated with the way one views their sexual

self schema. Each adjective is rated on a 6-point rating scale. Scores from these individual measures were combined to create a composite score of sexual schema for ease of analysis.

Sexual affect (Sexual distress).

Sexual affect was defined by how a person thinks, and therefore feels about his/her sexuality and the influence it has on sexual function. This was quantified through the amount of sexual distress (or negative thoughts about one's sexuality) present in participants. Sexual distress was measured by the Female Sexual Distress Scale – Revised (FSDS-R) and, with permission from the authors, adapted to measure sexual distress in both females and males to be called the Sexual Distress Scale (SDS) in the study. The 12-item instrument measures the concept of sexually related personal distress about sex life, assessing frustration, worry, guilt, unhappiness, embarrassment, stress, and anger using a 30-day recall period and a 5-point Likert scale (0=never to 4 =always). Responses were summed for an overall score with a score of 15 or higher indicating sexual distress.

Psychological distress.

Psychological distress was conceptualized as an aversive response to perceived internal and/or external stressors, which leads to actions aimed at addressing, adjusting to, or ignoring stressors. Psychosocial distress was operationalized through the use of the Brief Symptom Inventory (BSI) (Derogatis & Melisaratos, 1983). The BSI is a 53-item scale of self-reported psychological symptoms experienced during the previous seven days. Nine symptom dimensions are measured using items rated on a 5-point Likert scale from “not at all” to “extremely”. One global index was used in the analysis: the Global Severity Index (GSI) with a test-retest coefficient of 0.90. A high score is interpreted to mean a high level of

psychosocial distress in all the BSI scales. Psychological distress was one of the dependent variables in hypothesis 2.

Quality of life.

Quality of life (QOL) was conceptualized as an individual's ability to function physically, emotionally, and socially within his/her environment at a level consistent with his/her own expectations (Church, 2004). QOL was operationalized in both samples through the use of the Short-Form-36 (SF-36) and the survivors were also asked to complete The Impact of Cancer Scale (IOC). These two instruments measured the dependent variable QOL in hypothesis 2. To differentiate between them in the data analysis, SF-36 was labeled as "overall quality of life" and the IOC will be labeled as "perception of cancer on quality of life."

The SF-36 is a 36-item Likert scale questionnaire that yields an eight-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures (Ware, 2000). The two SF-36 summary indexes, mental competency and physical competency were combined to create a composite score of quality of life. Higher scores indicate higher quality of life.

The Impact of Cancer Scale (IOC) is a 41-item, 5-point Likert scale questionnaire utilized to measure several cancer specific factors of quality of life in the long-term survivors (Zebrack et al., 2007). The scale's 41 items are comprised of 10 subscales (health awareness, body changes, positive and negative self-evaluation, positive and negative life outlook, life interferences, value of relationships, meaning of cancer, and health worry). All items were scored on a 5-point Likert-type scale ranging from *Not at all* to *Very Much*. The scale has two

subscales, Positive Impact and Negative Impact, both used in this study to assess the perceived positive impact and negative impact of cancer on quality of life. Higher scores indicated greater impact on each of the subscales.

Age (control variable).

Current age, reported by both survivors and healthy peers, along with age at diagnosis as reported by the survivor participants was collected on the demographic questionnaires (Appendix A).

Data Analysis.

Data collected on the study instrument were analyzed using the Statistical Package for Social Sciences (SPSS) software, Version 18.0. Distribution frequencies and measures of central tendency and variability were computed for demographic data. All the demographic data were tested for statistically significant differences between the sample's two groups – young adult cancer survivors and healthy peers – through comparing mean scores. Independent t-tests were utilized to explore any statistically significant differences between the variables of the sexual self in the two groups - supporting or rejecting hypothesis 1. Exploration for correlations among the study's variables were done using Pearson's correlation in bivariate analyses. Multiple regression analysis was used to test the study's multivariate H2, exploring relationships between the independent variable, Sexual Self, and the dependent variables, Psychological Distress and Quality of Life. After further exploration of the quantitative and qualitative data a path analysis was used to further test H2, specifically in young adult cancer survivors, seeking both direct and indirect contributions to the three

components of the sexual self, and perceived positive and negative quality of life. The .05 level of significance was used for all statistical testing.

Qualitative portion of study.

This research study utilized a QUANTqual methodology in gathering data through the use of several reliable and valid surveys and the use of a telephone focus group with randomly selected young adult cancer survivors. A QUANTqual study implies that the majority of data gathered on participants was quantitative in nature, with qualitative data gathered to “enliven and illustrate” (Padgett, 2008, p. 225) the quantitative findings. The focus group interview was guided by the adapted McGill Illness Narrative (2006) with ten randomly selected study survivor participants who identified they would be willing to be included in a focus group. Of these ten, eight participated in the focus group. The focus group was conducted via a telephone conference call with the selected participants in order to gather a further understanding of their knowledge and experience of cancer and its influence on their sexual self. The qualitative question explored through the use of the McGill Illness Narrative was “What was the young adult’s experience of cancer and how did it affect his/her sexual self”?

A telephone focus group was chosen as the qualitative methodology for several reasons. First and foremost, the nature of research is exploring a very personal topic and was asking for highly personal disclosure. Recent research has shown that focus groups on the telephone have been able to elicit more information on sensitive topics than those done face to face (Frasier et al., 2010). Second, based on this researcher’s professional experience, she knows this population to be very transient and to have both spontaneous and hectic schedules. Trying to coordinate face to face focus groups with the participants would have been

challenging, given that travel and work schedules might have competed. With participants on the telephone, they could speak from the hospital (which one participant did), their home, their car, or their office allowing for maximum flexibility.

Data collection.

At the end of the quantitative survey, young adult cancer survivor respondents were asked if they would be willing to participate in a focus group to further explore the sexual self of young adult cancer survivors. Interested participants were asked to provide their email and/or phone number where they preferred to be contacted. A random selection was utilized to select five women and five men who had reported on the survey that they would be willing to participate in a focus group. All participants had identified an email address to be contacted at and were emailed by the researcher with a letter of request. The letter of request summarized the study and the purpose of the telephone focus group, along with information on the fifty-dollar gift card they would receive at the completion of the focus group. Ten participants confirmed interest in the focus group. After polling the participants, the telephone focus group phone call was scheduled for a week night at 5:30 Pacific time to accommodate all time zone's and participants schedules. All participants were given a toll free number to call and of the ten, eight survivors participated and completed the group interview. All participants received a fifty-dollar gift card, however, one participant requested that his gift card be sent to a young adult support organization in his honor.

Qualitative Analysis.

The telephone interview was guided with open-ended questions from an adapted version of the McGill Illness Narrative with questions relating to the study's variables of

sexual self, psychosocial distress, and quality of life. The purpose of the interviews was to gain a richer understanding by allowing the young adults to come together and speak with their own voices from their own perspective of being a young adult cancer survivor.

Verbatim transcripts from the audio-taped telephone focus group were coded using open coding of the content and themes (Grbich, 2007). Themes elicited from the content analysis of the focus group were summarized and examined to discuss what supported and enhanced the quantitative data gathered. In addition, data was analyzed to examine further questions or information that the quantitative surveys were not able to capture. Atlas.ti, a qualitative data software, was used to facilitate the organization of the coding.

Findings

Quantitative demographic findings.

The majority of the young adult respondents in the study were female. Of the 167 young adults, 86.2% are female and 17.4% are male. There was no significant difference found between the healthy peer and survivor group and gender. Participants ranged in age from 18 to 40. Actual age was used in the analyses, but was recoded for ease of comparison into three age groups (18 to 25, 26 to 33, and 34 to 40) with the largest number of participants being between 26 to 33 years old in 46% of the cancer survivors and 48% in the healthy peers, ages 34 to 40 having the second highest group represented and 18 to 25 being the smallest represented group. There was no statistically significant difference in mean age by group. The majority of the sample (91.6%) identified as a non-minority with the remaining 8.4% identifying as a minority. No significant differences were found between groups by race/ethnicity. There was no significant difference in highest education achieved between the

two groups, with most participants achieving a minimum of a bachelor's degree. The distribution of the sample according to sexual orientation was found to be significantly different (likely due to the difference in size between the two groups), with the survivors reporting a much larger percent of persons who do not identify as heterosexual (15.9%) compared to their healthy peers (1.9%). Sexual orientation was recoded as Heterosexual and Other and demonstrated that the sample consisted of 88.6% of individuals whom identified as heterosexual and 11.4% identified a different sexual orientation ($\chi^2 = 7.182$, $df = 1$, $p < .01$). Reported age of when the individual became sexually active was also not significantly different between the two groups with the majority of respondents reporting their sexual activity began between the ages of 15 and 20. Relationship status was significantly different between the two groups with healthy peers reporting higher frequencies of marriage or committed relationships at 82% compared to 63% of the survivors ($\chi^2 = 5.927$, $df = 1$, $p < .05$). A surprising statistical finding was the percentage of young adults who reported at least one incident of non-consensual sex. Research has shown that 18% of all women and 3% of all men in the United States have been victims of rape (Tjaden & Thoennes, 2006). Although there was no statistically significant difference between the two groups, the percentage of non-consensual sex among all participants was higher than the U.S. statistics, with 23.9% of all females and 17.7% of all males reporting at least one incident of non-consensual sex. These statistics were startling.

Qualitative demographic findings.

The sample included three women and five men initially diagnosed with cancer between two and five years before data was collected. Four of the participants had more than

one cancer diagnosis. Of these four, two of the men were diagnosed with two different cancers upon initial diagnosis and two of the women had various recurrences or secondary cancers. Seven of the participants were considered to be in remission. However, of these seven one of the women reported she expected for the cancer to “show up again” (S2). One of the men had a stage four cancer. Cancers varied and included thyroid cancers, blood cancers, sarcomas, breast, and lung cancer. The mean current age of participants was 30 with a mean age at diagnosis of 27. Four of the male participants were either married or identified being in a committed partnership, one reported he was single and dating. Of the three women, one was in a significant partnership and the others were single and dating. Sexual orientation varied only slightly with one participant identifying as homosexual and all others as heterosexual.

Major study findings.

Bivariate correlation analysis was performed as a precursor to multivariate analysis. The correlation analyses found many correlations between the control variables, the various domains of the independent variable, and the dependent variables. Both the quantitative and qualitative findings supported this researcher’s assumption that young adult cancer survivors experience more negative sexual selves than their healthy peers and the effects of cancer continues to influence the survivors’ current perception of their sexual self.

Quantitative findings.

Survivorship status, psychological distress, and overall quality of life.

Survivorship status and psychological distress were negatively correlated with overall quality of life. The higher the psychological distress in young adult cancer survivors, the

lower the quality of life scores ($r = -.440, p < .01$). In healthy peers, the higher the psychological distress, the lower the quality of life scores ($r = -.476, p < .01$).

Correlations were found in both groups, survivors and healthy peers, and several of the domains of the independent variable (sexual self), and one of the dependent variables (psychological distress). In both groups, the sexual self domain of sexual function were negatively correlated with psychological distress (survivors: $r = -.253, p < .01$; healthy peers: $r = -.353, p < .01$). Both healthy peers and young adult survivors demonstrated when sexual function was low, the more likely the participant was to report greater psychological distress scores. The sexual self domain of sexual distress and psychological distress were positively correlated for survivors ($r = .345, p < .01$) and trending towards significance in healthy peers ($r = .268, p = .052$). That is, regardless of cancer survivorship, when a young adult reported higher the sexual distress, the more likely the participant was to have greater psychological distress scores.

Correlations were found between the three domains of the independent variable, sexual self, and the dependent variables of quality of life. When a young adult cancer survivor identified high sexual distress, the more likely the participant was to have lower the overall quality of life ($r = -.317, p < .01$). Sexual esteem was negatively correlated with the perceived negative impact of cancer on quality of life. The lower the sexual esteem, the higher the perceived negative impact of cancer on quality of life in young adult cancer survivors ($r = -.321, p < .01$). Sexual function was negatively correlated with the perceived negative impact of cancer on quality of life. The poorer the sexual function, the higher the perceived negative impact of cancer on quality of life in young adult cancer survivors ($r = -.339, p < .01$). Sexual

distress was positively correlated with the perceived negative impact of cancer on quality of life. The higher the sexual distress, the greater the perceived negative impact of cancer on quality of life in young adults survivors ($r = .427, p < .01$).

Many of the domains of the study's independent variable of the sexual self were correlated. Survivorship status and sexual schema were positively correlated with sexual esteem. Both healthy peers and cancer survivors demonstrated that the more positive the sexual schema the higher the sexual esteem score in young adults ($r = .597, p < .01$ and $r = .417$, respectively, $p < .01$). In both healthy peer and cancer survivor young adults, those who identified greater sexual function, the more likely they were to report higher sexual esteem ($r = .627$ and $r = .497$, respectively, $p < .01$). In healthy peers and cancer survivors, the higher the sexual distress the more likely the participants were to report lower sexual esteem in young adults ($r = -.548$ and $r = -.434$, respectively, $p < .01$). Young adult cancer survivors demonstrated that the higher the sexual function, the more likely they were to report more positive sexual self schema scores ($r = .209, p < .05$). The higher the sexual distress reported by both a young adult with no history of cancer and a cancer survivor, the more likely it was that the participant also reported lower sexual function ($r = -.682$ and $r = -.388$, respectively, $p < .01$).

Cancer survivorship, the impact of cancer, and overall quality of life.

When a young adult cancer survivor reported a higher negative perception of the impact of cancer on quality of life, the more likely it was that study participant also reported lower overall quality of life scores ($r = -.294, p < .01$).

Cancer survivorship, psychological distress, and the impact of cancer.

Psychological distress was positively correlated with the negative perception of cancer on quality of life. That is, the higher the psychological distress reported, the more likely the young adult cancer survivor was to experience a greater negative perception of cancer on quality of life scores ($r = .534, p < .01$).

Testing H1.

Independent t-tests were used to test Hypothesis One. H1 hypothesized that controlling for age, young adult cancer survivors would demonstrate more negative sexual selves than their healthy peers as identified by lower sexual functioning, lower sexual esteem and higher sexual distress.

Hypothesis 1 was supported with the exception that current age and the scores from the sexual self schema scales did not prove to be statistically significant. However, young adult cancer survivors reported significantly higher psychological distress levels ($M = 1.1, SD = 0.6$) than their healthy peers ($M = 0.7, SD = 0.4$) ($t = 5.017, df = 137.862, p < .001$). Additionally, young adults with cancer reported lower overall quality of life ($M = 45.4, SD = 3.2$) than their healthy peers ($M = 47.7, SD = 37.3$) ($t = -3.918, df = 85.866, p < .001$). When exploring the domains of the sexual self, sexual function, sexual esteem and sexual distress were all significantly different between the two groups. Young adults with cancer reported significantly lower levels of sexual functioning or sexual inactivity ($M = 21.0, SD = 9.4$), than their healthy peers ($M = 29.5, SD = 5.8$) ($t = -6.918, df = 147.006, p < .001$). Young adults with cancer reported significantly lower sexual esteem ($M = 21.7, SD = 11.6$) than their healthy peers ($M = 27.3, SD = 8.8$) ($t = -3.379, df = 86.87, p < .001$) and higher sexual

distress scores ($M = 21.2$, $SD = 13.6$) than their healthy peers ($M = 9.7$, $SD = 9.0$) ($t = 6.39$, $df = 144.91$, $p < .01$).

Testing H2.

Multiple regression analyses were used to test the multivariate Hypothesis Two. H2 hypothesized that controlling for age and age at diagnosis, the more negative the sexual self, the higher the psychological distress and lower the quality of life in young adult cancer survivors.

Hypothesis 2 was partially supported. Initially, the hypothesis called to control for age and age at diagnosis. However, it was discovered that both these variables were almost perfectly correlated (0.96) in a bivariate analysis. Therefore, this researcher chose just to control for age at diagnosis in the multiple regressions. Controlling for age at diagnosis was not significant with psychological distress or the negative impact of cancer scale scores, thus this variable was not included in the final analysis. Controlling for age at diagnosis was significant with the dependent variable of quality of life. When examining the domains of the sexual self (sexual function, sexual esteem and sexual distress), after removing age at diagnosis as a control variable, all were found to have a statistically significant relationship with at least one of the dependent variables.

Controlling for age at diagnosis, sexual distress was predictive of overall quality of life as measured by the SF-36 ($F = 3.974$, $p < .004$). The older the survivor was at diagnosis and the less sexual distress, the higher the QOL. Sexual distress is the stronger predictor ($\beta = -.345$) than age at diagnosis ($\beta = .242$) of QOL. The whole model (all domains of the sexual self) explained 20.1% of the variance in overall quality of life.

Controlling for age at diagnosis, age at diagnosis was the only statistically significant predictor ($p < .05$), with sexual esteem trending toward significant ($p < .08$) in predicting positive perception of cancer on quality of life, as measured by the IOC scale ($F = 2.403$, $p < .05$). The younger the survivor at diagnosis and the higher the sexual esteem, the higher the positive QOL of cancer survivors. Age at diagnosis was the stronger predictor ($\beta = -.244$) than sexual esteem ($\beta = .246$). 12.8% of the variance in the IOC positive subscale was explained by the whole sexual self model.

Multiple regression analyses were rerun without any control variables to test the independent variables making up the sexual self on the dependent variables of overall quality of life, perception of cancer on quality of life, and psychological distress. When the models of the effect of the sexual self on psychological distress and the negative perception of cancer on quality of life were run, both models were found to be significant. All domains, except the sexual self schema, were found to be predictive of at least one of the dependent variables.

Sexual distress was predictive of quality of life as measured by the negative perception subscale of the IOC ($F = 5.253$, $p < .001$). The greater the survivor's sexual distress ($\beta = .319$), the lower the negatively perceived quality of life. The whole model explained 20.2% of the variance in the Impact of Cancer negative subscale.

Sexual distress was predictive of psychological distress with sexual function trending toward predictive of psychological distress as measured by the Brief Symptom Inventory ($F = 4.944$, $p < .001$). The greater the sexual distress and the lower the sexual function, the greater the psychological distress of young adult cancer survivors. Sexual distress was the stronger

predictor ($\beta = .339$) than sexual function ($\beta = -.226$). The whole model explained 19.2% of the variance in the BSI.

Additional quantitative findings.

When controlling for age in healthy peers, none of the models determined significant predictors of quality of life and psychological distress. Additionally, even without control variables, the domains of the sexual self in the healthy peers remained non-significant predictors of quality of life and psychological distress. However, when controlling for age in young adult cancer survivors, domains of the sexual self were significant predictors of psychological distress ($F = 4.828, p < .001$) and overall quality of life ($F = 3.990, p < .004$). Important to note is that these results are different than when controlling for age at diagnosis, which was not significant with psychological distress.

Path analyses were run to test the researcher's proposed conceptual model of the sexual self. The first path demonstrates that there is a direct effect of sexual esteem on sexual distress, the lower the esteem, the higher the sexual distress. A direct effect of sexual esteem on sexual function was also identified, where lower esteem may directly influence lower sexual function. In addition, higher sexual distress directly influenced lower sexual function. Therefore, sexual esteem indirectly affected sexual function through sexual distress. When a survivor's sexual esteem was low, sexual distress was high and sexual function was low. As would be expected, none of these variables have a direct effect on the positive perception of quality of life. A positive quality of life may not be perceived if a young adult survivor has low sexual esteem.

The path that included looking at the effect sexual esteem can have on sexual distress, sexual distress on sexual function, and sexual function on perceived negative quality of life, was supported. The path demonstrated that there was a direct effect of sexual esteem on sexual distress, the lower the esteem, the higher the sexual distress. Sexual esteem also had a direct effect on sexual function, the lower the sexual esteem, the lower the sexual function. Sexual esteem had an indirect effect on sexual function through sexual distress; the lower the sexual esteem the higher the sexual distress, the lower the sexual functioning. Sexual distress had a direct effect on the perceived negative impact of cancer. Sexual esteem had an indirect effect on negatively perceived quality of life through sexual distress. Therefore, this path supports the researcher's conceptual model that a negative sexual self (low sexual esteem, high sexual distress, and low sexual function) can negatively influence perceived quality of life. Young adults who identified lower sexual esteem, higher sexual distress, and lower sexual function demonstrated a more negative perception of the impact of cancer on their life.

Quantitative summary.

The quantitative portion of the study confirms that the event of cancer may affect the sexual self of survivors such that there is a statistically significant difference from the sexual self of non-affected peers. The three domains of the sexual self (sexual esteem, sexual distress, and sexual function) were all significantly predictive of quality of life measures and psychological distress in young adults with cancer. This data indicates that the sexual self is an important aspect of quality of life and when a young adult survivor has a more negative sexual self, their psychological distress is higher. The qualitative data confirm these findings

and enrich the researchers understanding of why a more negative sexual self may be present in young adult survivors and how this may or may not affect perceived quality of life.

Qualitative findings.

The qualitative portion of the study introduced the perspectives and voices of a small number of the young adult cancer survivor participants. The eight participants in the focus group included five males and three females ranging in age from 21 to 38. Diagnoses also varied and included three individuals who had received multiple cancer diagnoses. Three of the individuals were in committed partnerships, two were married, and three were single and/or dating.

Guided by the semi-structured McGill Illness Narrative to inquire about the experience of cancer and their perceptions of how their sexual self had been affected by the cancer diagnosis, six key themes emerged:

Theme 1. Late effects of treatment continue to interfere with the sexual self.

Theme 2. Physical limitations trigger mental limitations that influence the sexual self.

Theme 3. Perceptions of past sexual self influence perceptions of present sexual self.

Theme 4. Communication with partners influences perceptions of sexual self.

Theme 5. Medical procedures negatively influence intimate touch.

Theme 6. Communication with health care providers highlights importance of sexual self.

These key themes appear to offer greater meaning and support to the quantitative findings and may provide more of an explanation of how the various domains of the sexual self are affected by the diagnosis of cancer and its treatments.

In agreement with the quantitative findings, the eight young adult cancer survivors reported changes in their sexual selves after their cancer diagnosis. These changes were reported to directly affect their relationship stress and psychological distress, in addition to their quality of life. Many of the participants reported experiencing late effects that were not necessarily sexual in nature but impinged upon their ability to sexually perform as they did prior to cancer. For example, one young man reported he had severe graft versus host disease, and felt as though any time he bent his knees in a certain position that his skin would rip. This physical distress affected his ability to engage in many sexual positions, which contributed to a lower sexual esteem and higher sexual distress. The negative thoughts reported by many of the participants about their body image, the late effects of treatment, changes in their sexual performance and thoughts of being rejected by a partner all contributed to lower sexual esteem. This lower sexual esteem increased sexual distress. Sexual distress was identified as a response to the negative thoughts and led to negative feelings of discouragement, depression and anxiety. Unfortunately, the negative thoughts and increased sexual distress lead to greater sexual dysfunction or decrease in sexual behavior in the young adult cancer survivors.

In addition, supportive to the qualitative research, when a male young adult survivor identified lower sexual function, psychological distress was reported higher. The men also had more incidences of reporting that lowered sexual function and greater sexual distress was affecting their relationships. Beyond increasing the sexual distress, a few of the individuals reported that they felt guilt over their partner being directly affected by the cancer and that, even years after, cancer continued to influence their sexual relationship. During the focus

group, although the women identified some lower sexual functioning, their psychological distress tended to be associated with the loss of fertility and the scarring on their bodies.

As revealed in the focus group, a contributing event to the more negative sexual selves identified could possibly be due to the lack of information provided by the health care team regarding sexual health. It was revealed in the focus group that the lack of information provided by the health care providers was perceived by the survivors to mean that their sexual health concerns and needs were unimportant. All of the young adults identified greater psychological distress over what they perceived to be the dismissive responses of health care providers about the topic of sexuality. Many of the young adults identified that the dismissive attitudes of their health care providers decreased sexual esteem, increased sexual distress, and this directly increased their psychological distress. The same response was reported among participants who thought their partners were disappointed and/or frustrated with their sexual life, leading to increased distress. One young man reported that the added pressure from his partner to be able to sexually perform only contributed to his distress and decreased his sexual function because “it’s going to be a failure anyway” (S1). When communication was stronger between survivor and partner, or if a survivor identified comfort with discussing the issues surrounding sexual health, the survivor’s sexual esteem appeared to be higher. The positive thoughts associated with a higher sexual esteem appeared to lead to decreased negative thoughts about their sexuality and, therefore, their sexual distress was low and their sexual function was not further complicated by a lowered esteem and higher distress.

In addition to the information that supported the quantitative findings, an additional theme emerged within the focus group about how the experience of being “poked and

prodded” for medical procedures negatively affected the sexual self. These actions by health care providers were perceived as invasive and as very intimate acts. Invasive procedures (e.g., un-gowning, blood draws, physical screenings) by “strangers” (S7) continue to influence how some of the young adults currently perceive intimate touch from a partner. Many of the participants reported an increase in their desire for “safe” (S4) intimate, non-sexual touch by their partner during and well after their cancer diagnoses. A struggle was identified between wanting to be touched or held by their partner, but experiencing moderate anxiety over being touched by anyone in an intimate way, as touch has been integrated as painful or negative. This new perception of touch appears to have negatively influenced their sexual selves. However, for the young adults who have been able to incorporate communication with their partners about their need for non-sexual intimate touch, the sexual selves were less negatively influenced.

Other survivors identified one possible reason for their more negative sexual self as due to the guilt they feel for their partner having to ‘pay for’ the diagnosis, long after the treatments have ended. Thoughts such as “She gave up a lot for me” and “I’ll never be able to repay her” led to feelings of guilt. The feelings of guilt seemed to increase sexual distress as they tried to manage the sexual consequences of treatment and knowing that these consequences would also affect her. Interestingly, this guilt was not identified as much by the women in the focus group, rather, guilt about infertility was identified by the female participants whose fertility had been affected.

Qualitative summary.

The qualitative findings supported the quantitative data and provided greater understanding of the possible explanations of how a young adult cancer survivor's sexual self is negatively or positively affected by the event of cancer. Exploring the experiences of the young adult cancer survivor via a telephone focus group allowed this researcher to ask questions in an anonymous setting and gather rich data on a sensitive topic.

Significance of Findings to Social Work

This researcher's professional experience has been confirmed in the qualitative portion of this study in that young adult patients' sexuality is overlooked in the assessment of quality of life issues in treatment and survivorship clinics. Too often, it seems that the focus on treatment of young adult survivors is "cure" and neglects secondary and late effects like infertility, osteoporosis, chronic pain, disfigurement, and sexual health, which could have potentially devastating implications on a person's distress levels and quality of life. This study was developed in the hope that it would further elucidate the experience of young adult cancer survivors' sexual selves.

Implications for theory and practice.

Beck (1982; Beck et al., 1986) and colleagues proposed that cognition involves both content and process of thought and, consequently, persons are capable of evaluating and modifying their own thoughts. Beck (1982) used the term "distorted thinking" regarding problematic thoughts and asserted that cognitions do not directly cause the affect or feeling (e.g., sadness), but that cognitions are linked to a particular affective state, such as depression. How people feel and behave is largely determined by their cognitions, and changing how

people structure their experience is the most efficient way to change distorted feelings or behaviors. As this research began to uncover, a young adult cancer survivor's sexual behavior may be largely determined, for example, by the way he thinks about his sexual dysfunction caused by the surgical procedure done to remove the cancer. If he interprets this sexual dysfunction with the distorted thought of "I'm not a competent lover," most likely the feelings attached to this thought will be negative, such as sexual distress, leading to ongoing sexual dysfunction and negative sexual behavior (e.g., isolating himself).

Another influential cognitive theorist, Ellis (1975), is known for the term "irrational beliefs" and argues that an activating event (e.g., sexual dysfunction) can stimulate a belief about one's self, which then influences the behavior and consequences of the behavior. Ellis believes that people must accept responsibility for their own emotional disturbance and maladaptive behavior, and in order to create change she must change the way she thinks about her thoughts. Although an irrational belief certainly can perpetuate sexual distress and increase sexual dysfunction, it would not be helpful to ask a young adult to say that her fear of pain during sex (due to decreased vaginal lubrication) is due to an irrational belief or maladaptive behavior. In addition, it would not be possible to change the event of cancer or the negative thoughts associated with fear of painful sex, if sex is painful due to the consequences of treatment. Integrating the Cognitive-Integrative Perspective (C-I) (Berlin, 2000) can assist in addressing the events like cancer or consequences of these events that do not necessarily need to be further interpreted.

C-I emphasizes the clinical importance of assessing the person's environment and objective interpretation of his problem to assist with solving any practical problems that may

impinge upon his progress. For example, if a client is living in an unstable living situation and reports distress over not being able to sleep due to being fearful of an attack at night, to dismiss this fear as irrational would not be effective (Berlin, 2002). Similarly, if an individual has a significant deformity that inhibits sexual function, this would not be dismissed but rather addressed, and the individual would be encouraged to find new ways of sexual satisfaction. The health care professional would first address the objective concern in addition to addressing the subjective interpretation of the problem. This researcher believes that the C-I perspective has great clinical promise in helping identify and improve how a young adult cancer survivor could improve a negative sexual self perception. For example, if a young adult should report that his physical deformity prevents him from sexually engaging with his partner, the clinician would not dismiss this as an ‘irrational’ or ‘distorted’ thought, but rather challenge the conclusion he was making about himself from this new reality (e.g., “I’m never going to be able to sexually perform”). By addressing the objective information, or the interpretation of the event, the clinician can begin to explore other thoughts and behaviors that can be in response to the new sexual limitations (e.g., “I am still capable of being creative and I can work toward defining my new normal” – leading to feelings of competence and hope).

Supportive of cognitive theory and the C-I perspective, this study’s path analyses confirmed that negative thoughts about one’s sexuality (sexual esteem) directly affect both increased sexual distress (affect) and decreased sexual function (behavior). In addition, the more negative the sexual self, the more negative the perceived quality of life. Therefore, if applying a C-I based intervention, in order to create a positive change in the young adult’s

sexual self, the clinician would start by acknowledging the direct changes that cancer and its treatments can create. Addressing the objective and often unchangeable outcomes of cancer and its treatments can assist in normalizing the changes and challenge the young adult to think differently about these changes. The clinician would then assist the young adult in creating a new positive or more hopeful thought(s) attached to their cancer affected sexuality, improving sexual esteem. By increasing sexual esteem, the clinician would directly decrease sexual distress, improving sexual function and perceived quality of life.

Implications for research and practice.

This study was aimed at understanding and uncovering the sexual selves of young adult cancer survivors, and to proposing a new conceptual model of the sexual self. Understanding the sexual self of young adult survivors could directly influence how oncology health care professionals, including social workers, are trained to evaluate and approach the biopsychosocialsexualspiritual needs of patients. The data from this study could potentially influence the need for the further training of oncology social workers in the assessment of patients' sexual health and intimacy needs.

In order for oncology social workers and other oncology professionals to be able to assist young adults in improving their quality of life, it is especially important to understand how their sexual selves are influenced by current thoughts, feelings, and behaviors. The qualitative findings of this study helped to shed light on possible reasons for increased negative sexual selves in young adult cancer survivors. In addition to the direct attack that cancer and its treatments can have on the sexual self, the awareness of how violating procedures of cancer care were reported to be are critical. This is especially pertinent given

that over a quarter of the young adults who participated in this study reported one or more non-consensual sexual experiences (23.9% of women and 17.7% of men). These statistics were startling. On average, data from studies in the U.S. report that 18% of all women and 3% of all men are victims of rape (Tjaden & Thoennes, 2006). Therefore, should an oncology professional not inquire about a patient's sexual health history, or history of sexual abuse, he or she may unintentionally trigger traumatic memories and responses. This in turn could not only exacerbate the negative effects on the sexual self, but also have other negative consequences to the required trusting relationship between patient and provider. This study's data may indicate it could benefit the patient and provider if the history included questions regarding previous traumatic sexual experiences. In addition to the skill of screening, as they are trained to obtain a thorough biopsychosocial history, social workers have the ability to advocate for patients and assist in creating a safe environment for patient assessment and care. Utilizing the data from this study on the percentage of non-consensual sexual incidents among young adults should raise caution the next time a professional provides a physical examination.

An understanding of the sexual self will lead to a comprehensive assessment of the needs of young adult cancer survivors and to better treatment that will address an important aspect of quality of life. Based on the findings, several key points are worth considering in their application to social work knowledge and practice and implications for future research:

- 1) The cancer affected sexual self of young adult survivors appears to be different than the sexual self of non-affected healthy peers. This research supported the proposed conceptual model of the sexual self and identified that sexual esteem can have a direct effect

on sexual distress, sexual distress on sexual function, and sexual function on perceived negative quality of life. Therefore, identifying negative sexual esteem could lend itself to early intervention and psychosocial treatment, decreasing sexual distress and improving sexual function or more positive sexual behaviors. Furthermore, interventions targeted towards improving patients' sexual esteem could have direct and indirect effects on quality of life. In addition, it is recommended that further investigation of this model be implemented and this study be duplicated in various settings to improve the generalizability of the results. Replication of this study and development of a screening instrument to assist in the provider's ability to better identify and address the sexual health needs of cancer survivors.

2) Social workers and other health care practitioners who address the sexual self of survivors in their practice are encouraging, normalizing, and validating that their patients are sexual beings and have sexual needs regardless of physical, emotional or psychological constraints. The primary goal of addressing and assessing sexuality is to help patients achieve whatever degrees of interpersonal intimacy and sexual satisfaction they desire (vonEschenbach & Schover, 1984). Mackelprang (1993) states:

The emphasis social work places on holistic intervention on behalf of clients along with an empowerment oriented intervention strategy, uniquely prepares social workers to help clients with disabilities and their partners cope with the many psychosocial changes that accompany disabilities. Social workers who are prepared with counseling skills, and disability specific sexual knowledge can have a major influence on positive psychosexual development and adjustment of clients with disabilities and their

partners. It is up to the profession and up to the individual social workers to meet this important need. (p. 86 - 87)

Reports have identified that patients welcome inquiries from their oncology staff about their sexuality and would be open to the opportunity for discussing their sexual health concerns (Cull, 1992; Canada et al., 2005; Schover, 1999). This research study confirmed young adults are willing and eager to discuss their sexual selves and the lack of information provided decreased sexual esteem, increased sexual distress and affected quality of life and psychological distress. Therefore, it is important for health care professionals to understand the impact of cancer on the sexual self along with the best models of practice to address the topic with their patients.

3) Although some models of assessment and intervention have been established to address the sexual health needs of persons with cancer, there is need for further evidence-based practices to identify disruptions in and interventions for the sexual self within various clinical settings. Social work's core values and principles align with the goals and principles of evidence-based practices. Empirically-based biopsychosocial interventions should focus on the best possible treatment options for the client, with the goal of enhancing optimal functioning through the recovery and rehabilitation (Meuser, Drake, & Bond, 1997). As awareness improves on the long-term survivorship needs of childhood, adolescent, and young adult (AYA) cancer survivors, it is essential that oncology social workers reinforce the value and importance of evidence-based practice in order to improve all aspects of quality of life.

There is substantial literature looking at the impact that cancer and its treatments have on adults' sexual health and sexual function; however, most of this literature has examined

individuals with a diagnosis that directly affects a sex organ, like breast or testicular cancer, and does not address the general cancer population. Although there has been a heightened awareness of fertility issues in young adults, there are few published articles and even fewer resources for young adults to talk openly about their sexuality. The young adult cancer survivor population has, in so many ways, been drastically isolated from other cancer populations and are marginalized or left behind during follow-up visits with their oncology healthcare team. As defined by the Institute of Medicine (2001), evidence-based practice integrates best research evidence and clinical expertise with patient values. No studies have explored evidence based practice models assessing sexual health that are applicable in both inpatient and outpatient settings with AYA survivors. Future studies can explore various sexual health assessment and intervention models, such as the PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Therapy) model (Annon, 1976), with the goal of observing improvement in the sexual self and perception of quality of life. The PLISSIT model for sexual assessment has been well-utilized, written about, and accepted as a sequential model of sexual health assessment and could be a strong intervention model for oncology social workers and their patients (Annon, 1976; Claiborne & Rizzo, 2006; Rubin, 2005; Shell, 2003; Taylor, 2006). In addition to patient focused interventions, educational interventions for oncology professionals to help improve knowledge, comfort, attitude, and approach of sexual health with patients may assist in improving the likelihood that patients' sexual selves are addressed.

Given the time and resource constraints many oncology social workers face, evidenced-based practice research and any model selected must be flexible and applicable to

the social worker's expected role in order to be approved for the training. With many oncology practice settings taking on a transdisciplinary approach to patient care, collaboration with other professionals, would be essential to the success of the research and intervention. Further investigation of outcomes could explore any differences between the intervention being provided by a nurse, psychologist, or social worker.

Conclusion

This chapter provided a background of the problem, the theoretical support, and depicted the relationships and differences in the cancer affected sexual self of young adults as compared to healthy peers. In addition, the relationships between the sexual self, quality of life and psychological distress were explored. The preceding discussion revealed the influence of low sexual esteem, high sexual distress, and low sexual function on various quality of life measures. The findings reinforced the conceptual model of the sexual self and the possible negative impact a diagnosis of cancer can create. Interesting to the findings was the data that evolved from the qualitative interviews to assist in interpreting the possible reasons for the changes in the sexual self. The perception of the lack of sexual health information provided to the survivors was a possible influence on the more negative sexual self perception, in addition to the relationship challenges the survivors faced. Path analyses confirmed that sexual esteem does influence sexual affect and sexual function and, therefore interventions designed to address sexual esteem may improve the sexual self of cancer survivors. Analyses of the quantitative and qualitative findings allowed for greater information to be gleaned on a topic that is sensitive in nature.

Limitations and biases.

This study warranted identification of limitations and potential biases in interpreting the findings. First, the study sample was very small. It consisted of 167 young adults, with the majority ($n = 113$) being cancer survivors leaving a small comparison group ($n = 54$). The aim of this study was to explore the difference in the sexual self of cancer survivors and introduce a new conceptual model to define the sexual self. While a larger sample may have garnered additional information, the groups were similar across most of the demographics. However, diversity of the demographics in both groups was certainly limited, with the majority of participants being Caucasian/white and female. Interestingly, a greater number of men actually participated in the qualitative study than women. Additionally, as reported, a greater percentage of the healthy peers also identified as being in a committed relationship or married with a greater percentage of young adults reporting being single/divorced/dating. It is unclear whether a diagnosis of cancer has any bearing on this statistic. Future research could explore whether a diagnosis of cancer has affected marriage or relationship status of young adults diagnosed with cancer. However, the qualitative data gathered did not support the quantitative findings, as five of the eight survivors were married or in a committed relationship. While the sample size, limited gender and ethnic variations, may limit generalizability to the larger cancer survivor population, findings from qualitative analysis supports those from the quantitative analysis. This allows for greater transferability to the young adult survivor population (Lincoln & Guba, 1985).

Second, there are clear limitations of an exploratory study with a cross sectional design. These limitations include not being able to measure change over time, and thus

establishing cause and effect is not possible. Increased weakness to the design was participant self-selection and self-report, decreasing generalizability. Therefore, it is more likely that participants who had an interest in the sexual self of cancer survivors, or those invested in the organizations that advertised the study, responded. Although improved by utilizing a qualitative interview, surveys only provide limited subjective descriptions of what the participants' experiences had been. This may be particularly true for a sensitive subject matter like sex, as the participant may not have felt as comfortable answering the questions as honestly as their experience may have been.

Third, there were certainly limitations within the chosen instruments and demographic information gathered. Because sexual activity was not clearly defined at the beginning of the study participants were left to subjective interpretation of the term. Future research exploring the sexual self of cancer survivors should be clear on a definition of sexual activity so there is less subjective interpretation influencing responses. Lindau et al., (2007) provide a clearer definition stating, "By sex or sexual activity we mean any mutually voluntary activity with another person that involves sexual contact, whether or not intercourse or orgasm occurs" (p. 763). Although the survey instruments and demographic questions were chosen to be as neutral as possible to sexual orientation and practices, making no assumptions about vaginal or anal penetration, it could have been strengthened by more clearly defining sexual activity. Some persons may not consider oral sex or masturbation as "sexual activity" and therefore, the data gathered could have been limited. Creating a clearer definition is especially important with a value-laden topic like sexuality. Beyond more clearly defining sexual activity, it would have been helpful to capture the young adult survivor's perception of their sexual function

and relationships before and after cancer. Measuring for perceived changes in sexual activity before and after cancer would also help improve clinician's knowledge on how cancer affects sexual function and relationships and could lend to early intervention studies.

Additionally, as the study progressed, it became clear that there might be stronger instruments to measure the various domains of the sexual self. For example, although the gender specific sexual schema scales have been utilized over the past ten years in many clinical settings, including oncology, these scales did not seem to capture the sexual esteem (thoughts about one's sexuality) of young adults with cancer. Therefore, when measuring for sexual esteem in young adults with cancer, it would be important to identify a scale that better captures the thoughts that young adults have about themselves as sexual beings and predicts sexual affect. The sexual esteem subscale of the Sexuality Scale seemed to effectively measure how the young adults thought about themselves as sexual beings and was significant in predicting sexual affect.

A fourth limitation revolves around reliability in the qualitative data. Lincoln and Guba (1985) described the necessity to involve member checks in order to improve credibility. This would involve the use of colleagues to check analytic categories, coding, and interpretations. However, due to limitations in time and resources, only two colleagues assisted in a modified version of this process. In the quantitative part of the study, valid and reliable instruments were utilized although some were modified for the applicability to both genders, which also may reduce reliability.

In addition to these limitations, the interpretation and synthesis of these findings are certainly not without subjective bias. With a history of clinical oncology social work,

facilitating young adult support groups, and conducting workshops on sexuality after cancer, there was a personal interest in implementing an exploratory study on the sexual self.

Immersion in the qualitative data analysis revealed a sense of familiarity with other cancer survivors' stories heard by the researcher. While bias is possible, the researcher did have two other colleagues review and validate the study's coding schema and interpretation of qualitative data.

Relative to the quantitative findings, was that 82.9% of those who began the study survey abandoned it, with only 17.1% completing the survey. This could have been due to numerous factors. First, although on the first page of the survey there was an introduction letter, it is possible that young adults who did not qualify for the study (either because of age or years since diagnosis) did not realize were not qualified until they reached the second page of the survey. On the second page of the survey they were asked to identify themselves as a young adult diagnosed with cancer between the ages of 18 to 40 diagnosed 2 to 5 years ago, or a young adult with no history of cancer between the ages of 18 and 40. Second, the survey administrator does not provide information on when or where a participant stopped the survey. Therefore, it is possible that a participant may have been at the beginning and realized they were ineligible, or began the survey and became uncomfortable with the subject matter. Time may also have influenced their ability to complete the survey. Although the survey took on average 15 minutes to complete, participants may have stopped early or been interrupted and never revisited the site to complete the survey. The loss of possible responses certainly did not assist in the generalizability of the data collected.

Recommendations.

Through the exploration and identification of how the sexual selves of young adult cancer survivors are impacted by cancer and its treatments, health care professionals will be better able to directly improve quality of life measures. Identifying and assisting in the improvement of quality of life is one of the key components of an oncology social worker's job. Funding to support research examining quality of life and long-term or late effects of cancer treatments is at its peak and should be taken advantage of to further the betterment of the sexual self in cancer survivors. These studies could further support uncovering the experiences of young adult cancer survivors and their sexual selves, knowledge which would directly influence how oncology social workers evaluate and approach the biopsychosocialspiritualsexual needs of patients.

Oncology social workers should take advantage of the opportunity for future research opportunities exploring the impact cancer and its treatments have on sexuality in young adult cancer survivors. The numbers of young adult cancer survivors are on the rise, and it is this researcher's hope that oncology health care professionals will begin to understand the value of addressing the implications of the late and long term effects of cancer treatments on various aspects of patients' lives, including sexuality.

Appendix A

Young Adult Cancer Survivor Demographic/ Background Information

Please take a few moments to complete 19 background questions on you and your cancer that will help us understand your experience better.

1. Your gender
 - ☐ Male
 - ☐ Female
 - ☐ Transgender
 - ☐ Intersexed
2. Your age _____
3. Your age at diagnosis _____
4. The type of cancer you were diagnosed with _____
5. How would you classify yourself?
 - ☐ African American/Black
 - ☐ Asian/Pacific Islander
 - ☐ Caucasian/White
 - ☐ Hispanic
 - ☐ Multiracial
 - ☐ Other _____
6. What is the highest level of education you have completed?
 - ☐ Grammar school
 - ☐ High School or equivalent
 - ☐ Vocational or Technical School (2 year)
 - ☐ Some College
 - ☐ Bachelors Degree
 - ☐ Masters Degree
 - ☐ Doctoral Degree
 - ☐ Other _____
7. Relationship status (check all that apply)
 - ☐ Single – never married
 - ☐ Married
 - ☐ Single – Divorced/separated
 - ☐ Dating
 - ☐ Partnered

8. What is your sexual orientation?

- ☐ Homosexual
- ☐ Heterosexual
- ☐ Bisexual

9. At what age did you become sexually active? _____

10. Were you ever involved in a nonconsensual sexual experience?

- ☐ Yes
If yes, how old were you?
- ☐ No

11. Type of treatment you received (check all that apply)

- ☐ Chemotherapy
- ☐ Radiation
- ☐ Surgery
- ☐ BMT
- ☐ Hormones

12. Were you put into an early menopausal state or premature ovarian failure due to the treatments you received?

- ☐ No
- ☐ Yes
- ☐ Don't know
- ☐ Not applicable

13. Do you have any visible scars, current hair loss, or physical changes from your previous cancer treatments?

- ☐ No
- ☐ Yes (please describe)

14. Did a health care professional discuss the impact that cancer and its treatments may have on your fertility?

- ☐ No
- ☐ Yes (check all that apply)
 - ☐ Before treatment began
 - ☐ During treatment

☐ Once treatment was complete

15. If you were a minor at the time (under 18 years old), did a health care professional discuss the impact that cancer and its treatments may have on your fertility with your guardian or parent(s)?

- ☐ I was an adult
- ☐ No
- ☐ Yes (check all that apply)
 - ☐ Before treatment began
 - ☐ During treatment
 - ☐ Once treatment was complete
- ☐ Don't Know

16. Did an oncology professional discuss the impact that cancer and its treatments may have on your sexuality?

- ☐ No
- ☐ Yes, please describe

17. Overall, are you satisfied or unsatisfied with the information you were provided by your health care team regarding your sexuality after cancer?

- ☐ Very Satisfied
- ☐ Satisfied
- ☐ Somewhat Satisfied
- ☐ Not Satisfied
- ☐ Very Unsatisfied

18. Overall, are you satisfied or unsatisfied with the support you were provided by your health care team regarding your sexuality after cancer?

- ☐ Very Satisfied
- ☐ Satisfied
- ☐ Somewhat Satisfied
- ☐ Not Satisfied
- ☐ Very Unsatisfied

19. Have you ever seen a medical or mental health professional for sexual health concerns besides an annual physical screening or check-up?

- ☐ Yes
- ☐ No

Consent to Focus Group Participation: Please indicate your willingness to be randomly selected for participation in a focus group that will further explore and discuss your experience of cancer and its treatments.

- ☐ Yes, I am interested in participating in a focus group if my name is selected
Please provide your email address so I can contact you if you are randomly selected
- ☐ No, I am not interested in participating in a focus group.

Appendix B

Healthy Peer Demographic/ Background Information

Please take a few moments to complete 9 background questions on you that will help us understand your experience better.

1. Your gender

- ☐ Male
- ☐ Female
- ☐ Transgender
- ☐ Intersexed

2. Your age _____

3. How would you classify yourself?

- ☐
- ☐ African American/Black
- ☐ Asian/Pacific Islander
- ☐ Caucasian/White
- ☐ Hispanic
- ☐ Multiracial
- ☐
- ☐ Other _____

4. What is the highest level of education you have completed?

- ☐ Grammar school
- ☐ High School or equivalent
- ☐ Vocational or Technical School (2 year)
- ☐ Some College
- ☐ Bachelors Degree
- ☐ Masters Degree
- ☐ Doctoral Degree
- ☐ Other _____

5. Relationship status (check all that apply)

- ☐ Single – never married
- ☐ Married
- ☐ Single – Divorced/separated
- ☐ Dating
- ☐ Partnered

6. What is your sexual orientation?

- ☐ Homosexual
- ☐ Heterosexual
- ☐ Bisexual

7. At what age did you become sexually active? _____

8. Where you ever involved in a non-consensual sexual experience?

- ☐ Yes
If yes, how old were you? _____
- ☐ No

9. Have you ever seen a medical or mental health professional for sexual health concerns besides an annual physical screening or check-up?

- ☐ Yes
- ☐ No

Appendix C

Focus Group Interview Schedule Adapted from the McGill Illness Narrative Interview

1. When did you experience your sexual life difficulties for the first time? [Let the narrative go on as long as possible, with only simple prompting by asking, ‘What happened then? And then?’]
2. If you went to see a doctor, or spoke with your oncologist about the consequences of cancer and its treatments on your sexual life (including function, esteem and fertility) tell us about your visit to the doctor and about what happened afterwards.
3. What treatments or information did you receive (or expect to receive) as it relates to your sexual life? Do you feel that there was information or treatments that you didn’t receive?
4. In what ways do you consider your sexual life to be similar to or different from your healthy peers?
5. How has cancer changed your sexual life?
6. How has your view of your sexual life changed the way you feel or think about yourself?
7. How has your sexual life changed the way you look at life and relationships in general?
8. How has your cancer experience changed the way that others look at you and perceive your sexual life?
9. What has helped you through this period in your life?
10. How have your family or friends helped you through life after cancer and its impact on your sexual life (if any)?
11. How has your spiritual life, faith or religious practice influenced your exploration of your sexual life and or the changes you have experienced?
12. Is there anything else you would like to add?

Appendix D



National Catholic School of Social Service
Washington, DC 20064
202-319-5458
Fax 202-319-5093

THE CATHOLIC UNIVERSITY OF AMERICA
ONLINE
SURVIVOR CONSENT FORM

NAME: _____ **DATE:** _____

The name of this research study is: The Impact of Cancer and Its Treatment on the Sexual Self of Young Adult Cancer Survivors as Compared to Their Healthy Peers

Investigator: Sage Bolte, M.S.W.

Research Supervisors: Karlynn BrintzenhofeSzoc, Ph.D.; Barbara Early, Ph.D.; James Zabora, Sc.D.; Michael Plaut, PhD

You may contact Sage Bolte at 1-877-373-6015 or email her at CUA-slstudy@cua.edu if you have any questions or concerns.

Purpose: I understand the purpose of this research is to learn how the young adult cancer survivor's sexual life may have been impacted by cancer and its treatments in comparison to healthy peers. This study is being carried out in partial fulfillment for the requirements of a Ph.D. degree in social work at the Catholic University of America.

I understand that this study is trying to answer two questions.

1. Does cancer and its treatments impact the sexual life of young adult survivors compared to their healthy peers?
2. Does the way young adult cancer survivors think about their sexual life influence their overall quality of life?

Procedure: I understand that I will be asked to:

- Answer short questions by checking off the answer that is closest to what I think or feel.
- Take about 50 minutes to complete the multiple surveys.
- I will be asked to refer healthy peers who may want to participate directly to the website for them to decide if they want to participate. I understand that I am not required to refer any health peers to the study in order for me to participate.

I understand that the questions are about these five (5) topics:

- 1) My perceived quality of life.
- 2) My perception of my sexual life.
- 3) How I am dealing with being a cancer survivor.
- 4) The support systems I have available to me.
- 5) Information such as: my age, age at diagnosis, years of survivorship, my level of education.

Risks, inconveniences, and/or discomforts: I understand that I might be upset by some of the questions in this study. The questions ask about things in my life that can stir up my emotions. I do not have to answer any questions that I do not want to answer. I understand that I can stop, close down my computer and come back later and start where I left off, or I can stop and not return to the study if it is too upsetting to me. If I am in distress I may call or email the researcher and she will help me find support in my community.

Benefits: I understand that there is no direct benefit to me. The main benefit from being in this study is to understand the impact of a cancer diagnosis on young adults' quality of life, perception of their sexual life and sexual function and what services professionals can do in the future to better support young adults diagnosed with cancer.

Confidentiality: I understand that the researcher will separate my name from my data and replace it with a unique number. This will help protect my identity. The researcher is the only person who will see my questionnaire. The information from this study will be kept private in a locked file in a locked office and on a secure web site. In any report, only group information will be used. No information that will make it possible to identify me will be included. My answers to the questionnaire will only be used for research.

Voluntary Nature of the Study: I understand my decision to join this study or to not take part will not change how people treat me in the support agency that told me about this study. Also, my decision will never have an effect on how I am treated by The Catholic University of America if and when I do business with them. If I decide to take part in the study I am free to stop at any time. In fact no one else but me and anyone I tell, like my friend, spouse or partner, will know whether or not I have joined this study or not.

Contacts and Questions:

The researcher doing this study is Sage Bolte, M.S.W.

I may ask any questions I have either before or after the survey.

I may contact the researcher at 1-877-373-6015 or email her at CUA-slstudy@cua.edu

If I want to talk to someone other than the researchers, I can call:

The Secretary for the Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, D.C. 20064; Telephone (202) 319-5218.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I agree to take part in the study. Please print a copy of this form for your records.

Signatures: Please click below to show that you have read and understood what the study is and why we are doing the study. By clicking on the "*Begin Survey*" button you are telling us that you agree to take part in this study. If you do not agree to take part in the study simply close the window.

Appendix E



National Catholic School of Social Service
Washington, DC 20064
202-319-5458
Fax 202-319-5093

THE CATHOLIC UNIVERSITY OF AMERICA
ONLINE
HEALTHY PEER CONSENT FORM

NAME: _____ **DATE:** _____

The name of this research study is: The Impact of Cancer and Its Treatment on the Sexual Self of Young Adult Cancer Survivors as Compared to Their Healthy Peers

Investigator: Sage Bolte, M.S.W.

Research Supervisors: Karlynn BrintzenhofeSzoc, Ph.D.; Barbara Early, Ph.D.; James Zabora, Sc.D.; Michael Plaut, Ph.D.

You may contact Sage Bolte at 1-877-373-6015 or email her at CUA-slstudy@cua.edu if you have any questions or concerns.

Purpose: I understand the purpose of this research is to learn how the young adult cancer survivor's sexual life may have been impacted by cancer and its treatments in comparison to healthy peers. This study is being carried out in partial fulfillment for the requirements of a Ph.D. degree in social work at the Catholic University of America.

I understand that this study is trying to answer two questions.

3. Does cancer and its treatments impact the sexual life of young adult survivors compared to their healthy peers?
4. Does the way young adult cancer survivors think about their sexual life influence their overall quality of life?

Procedure: I understand that I will be asked to:

- Answer short questions by checking off the answer that is closest to what I think or feel.
- Take about 50 minutes to complete the multiple surveys.

I understand that the questions are about these three (3) topics:

- 1) My perceived quality of life.
- 2) My perception of my sexual life.
- 3) Information such as: my age, my level of education.

Risks, inconveniences, and/or discomforts: I understand that I might be upset by some of the questions in this study. The questions ask about things in my life that can stir up my emotions. I do not have to answer any questions that I do not want to answer. I understand that I can stop, close down my computer and come back later and start where I left off or I can stop and not return to the study if it is too upsetting to me. If I am in distress I may call or email the researcher and she will help me find support in my community.

Benefits: I understand that there is no direct benefit to me. The main benefit from being in this study is to help better understand the impact of a cancer diagnosis on young adults' quality of life, perception of their sexual life and sexual function compared to their healthy peers and what services professionals can do in the future to better support young adults diagnosed with cancer.

Confidentiality: I understand that the researcher will separate my name from my data and replace it with a unique number. This will help protect my identity. The researcher is the only person who will see my questionnaire. The information from this study will be kept private in a locked file in a locked office and on a secure web site. In any report, only group information will be used. No information that will make it possible to identify me will be included. My answers to the questionnaire will only be used for research.

Voluntary Nature of the Study: I understand my decision to join this study or to not take part will not change how the researchers treat me and the person who referred me will not know if I did or did not participate. Also, my decision will never have an effect on how I am treated by The Catholic University of America if and when I do business with them. If I decide to take part in the study I am free to stop at any time. In fact no one else but me and anyone I tell, like my friend, spouse or partner, will know whether or not I have joined this study or not.

Contacts and Questions:

The researcher doing this study is Sage Bolte, M.S.W.

I may ask any questions I have either before or after the survey.

I may contact the researcher at 1-877-373-6015 or email her at CUA-slstudy@cua.edu

If I want to talk to someone other than the researchers, I can call:

The Secretary for the Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, D.C. 20064; Telephone (202) 319-5218.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I agree to take part in the study. Please print a copy of this form for your records.

Signatures: Please click below to show that you have read and understood what the study is and why we are doing the study. By clicking on the "*Begin Survey*" button you are telling us that you agree to take part in this study. If you do not agree to take part in the study simply close the window.

Appendix F

Data Security for Online Survey

Data security protocol for online data

The online survey will be hosted by Vovici (www.vovici.com). Vovici caters to many large companies and to the U.S. military as well as to a number of Universities. The security policy of Vovici includes the following:

Surveys

When you publish your survey on our servers, we will provide you with a unique URL to display your survey. We will not provide this URL to any other person or entity, but we will provide your survey to any web browser requesting your unique URL. We may review your survey contents for violations of our Use Policy. If we determine your survey is in violation of our Use Policy, we will attempt to contact you and reserve the right to delete your survey and results from our systems.

Survey Results

It's your data. We will not attempt to read your survey results at any time unless explicitly instructed to do so by you, except that, solely with respect to any use of the EFM for CRM Module, we do review, process and provide analysis in aggregate form with respect to the results of specific format questions developed by Vovici regarding the likelihood of a survey respondent to refer others to the applicable products and/or services of an organization. We only disclose this information in aggregate form with respect to the survey results to these questions for the applicable organization for the EFM for CRM Module and not in any way that personally identifies you or your specific response to the questions in the survey. We do not own the contents of the data for your survey. Except for the limited analysis performed by us on the specific responses to the EFM for CRM Module, we only have access to your surveys for purposes of backup and troubleshooting. When your survey results are received by us, we will store them in a secure location. We will only allow your survey results to be downloaded directly into our desktop software or accessed through our online web interface. We have security measures in place to protect your results while stored on our servers and we will prosecute any attempt to access this information without authorization to the fullest extent of the law.

E-Mail Notification System

Our e-mail notification system stores your e-mail addresses on our server in a secured location. These e-mail addresses are kept on the server for tracking and click notification

purposes. Much like survey data, these addresses are yours, not the property of Vovici Corporation. Vovici technical support and development may examine these lists for support and troubleshooting purposes. We will not use or sell these e-mail addresses to anyone; any attempt to access your e-mail addresses without your authorization will be prosecuted to the fullest extent of the law.

Safe Harbor and EU Data Protection Requirements

Safe Harbor provisions are terms and conditions as set forth by the International Trade Federation of the United States Commerce Department that promotes data security and protection and procedures to insure that the terms and conditions are adhered to and supported by those companies who have agreed to the terms and conditions of Safe Harbor and have formally certified to that effect. Vovici Corporation has met the Safe Harbor requirements on 3/28/05 and has been placed on the Safe Harbor list of companies accordingly. This list and details on the Safe Harbor provisions may be found at: <http://web.ita.doc.gov/safeharbor/SHList.nsf/WebPages/virginia>. This certification is provided solely by the International Trade Federation of the United States Commerce Department and is not a certification by the TRUSTe program.

We reserve the right to disclose your personally identifiable information as required by law and when we believe that disclosure is necessary to protect our rights and/or comply with a judicial proceeding, court order, or legal process served on our Web site.

If we decide to change our privacy policy, we will post those changes to this privacy statement and other places we deem appropriate so that you are aware of what information we collect, how we use it, and under what circumstances, if any, we disclose it. We reserve the right to modify this privacy statement at any time, so please review it frequently. If we make material changes to this policy, we will notify you here or by means of a notice.

Retrieved from <http://www.vovici.com/about/privacy.asp> on October 2, 2007

Dr. BrintzenhofeSzoc has experience conducting online research using Vovici and Survey Monkey. The surveys will be accessible only through SSL (Secure Sockets Layer), a network protocol that encrypts the data between the server (the Vovici Hosting Service) and the client's application (a respondent's browser). The results will be downloaded and saved onto the researcher's computer on a regular basis. The computer will be password protected.

All data and data collection instruments will be kept in a secure site for the required three years after the completion of the study. At the end of this time all hard copies will be

shredded, the electronic copies will be deleted, and CDs with data will be shredded. The data on the Vovici site will be deleted by the principal investigator once all the analysis is complete.

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