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Exploring Cervical Cancer Treatments, Coping And Sexual Self-Concept After Cervical Cancer

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EXPLORING CERVICAL CANCER TREATMENTS, COPING ADAPTATION AND WOMEN'S SEXUAL SELF-CONCEPT AFTER CERVICAL CANCER

by

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DEDICATION

There are so many to extol and pay homage to on my behalf. Foremost is my husband, who has been a quiet and stable force in my life, filled with love for me since I was nine or ten years old. During my doctoral journey he was my wonderful anchor and always offered a wise ear for my laments. I also dedicate this to my sons because they always believed in me. Next, I honor my twin sister and am so thankful that we had each other during this process. At different times we each kept the other encouraged and/or focused. I acknowledge my other siblings, nieces and nephews, and so many friends, who all provided love and inspiration to me. I also remember in love and comfort the support I got from those who are no longer with me, but are forever a part of me.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

Due to the nature of cancer treatments, most cures are not without negative consequences. The long lasting impact of cancer on survivors and their families' lives can be a pervasive and unrelenting stressor on survivors (Barton-Burke & Gustason, 2007, Hewitt, Greenfield, & Stovall, 2006; Hughes, 2000; McCorkle et al. 2011). The long lasting impact is particularly true for women, who have experienced cervical cancer and the associated treatments (Bergmark et al., 1999; Clemmens, Knafl, Lev & McCorkle, 2008; Donovan et al. 2007; Herzog & Wright, 2007; Jensen et al., 2003). Cervical cancer treatment is stressful and dramatically impairs sexuality and affects how women adjust and cope after the disease and treatment (Andersen, 1999; Andersen & Cyranowski, 1993; Carpenter, Andersen, Fowler & Maxwell, 2009; Frumovitz et al., 2005). Unfortunately, women and their families usually contend with these circumstances in silence (Hordern, 2008; Park, Norris & Bober, 2009) and for prolonged periods of time.

There is a long history of physical, psychological and sexual sequalae and stress associated with cervical cancer and treatment (Andersen & Jochimsen, 1985; Cleary & Hegarty, 2011; Cull et al., 1993; Donovan et al., 2007; Mouga, 2000). Over time prognostic socio-demographic and clinical characteristics have been illuminated that could help predict disease, treatment and sexual health outcomes (Andersen & Cyranowski, 1994; Carpenter, Andersen, Fowler & Maxwell, 2009; Donovan et al., 2007; Levin et al., 2010). While not all of the prognostic factors have been empirically

supported, many were cited frequently in the literature. Prognostic factors that impact cervical cancer treatment outcomes that were often found in the literature, with and without empirical support included: treatment modality (Andersen & Cyranowski, 1993; Coker, Du, Fang & Eggleston, 2006; Mouga, 2000); time since treatment began (Culver, Arena, Antoni & Culver, 2002; De Groot et al., 2005); cancer stage (Andersen & Cyranowski, 1993; Brooks, Baquet, Gardner, Moses & Ghosh, 2000a; Shelton, Paturzo, Flannery & Gregorio, 1992; Merrill, Merrill & Mayer, 2000; Waggoner, 2003); age (Andersen, 1999, Andersen & Cyranowski, 1993; Coker, Du, Fang & Eggleston, 2006; Greimel, Winter, Kapp & Haas, 2009; Sawaya et al. 2001); race (Andersen & Cyranowski, 1993; Erwin et al., 2007; Howell, Chen & Concato, 1999; Merrill, Merrill & Mayer, 2000; Newmann & Garner, 2005); health status *(*Andersen & Cyranowski, 1993; Brooks, Baquet, Gardner, Moses & Ghosh, 2000; Carpenter, Andersen, Fowler & Maxwell, 2009; Hicks, Yap, Matthews & Parham, 2006); socioeconomic status [SES] (Andersen & Cyranowski, 1993; Brooks, Baquet, Gardner, Moses & Ghosh, 2000a; Eggleston, Coker, Williams, Tortolero-Luna & Martin, 2006; Morgan et al., 1996; Newmann & Garner, 2005); and education (Levin et al. 2010; Newmann & Garner, 2005; Schwartz et al., 2005), and relationship/family and social support (Andersen & Cyranowski, 1993; De Groot et al., 2005; Donovan et al., 2007; Thoits, 2010)

How well women coped with cervical cancer and the related issues was important to their survivorship. Which strategies might be helpful and when was equally important. No empirical studies were found that focused on the relationship between coping and its association to women's sexual self-concept. Coping is however, thought of as being embedded in stressful situations and when activated involved the person,

the context and the relationship between the person and the context (Folkman & Moskowitz, 2004). Although the current literature did not provide an empirical rationale for coping as a prognostic factor in sexual adaptation, a theoretical rationale existed for exploring coping as a mediator between cervical cancer treatment and women's sexual self-concept. Whether coping, specifically cognitive and religious coping would influence women's sexual self-concept was unknown.

Cognitive coping and religious coping strategies were chosen to be studied in this research based on the literature review (Folkman & Moskowitz, 2004; Harrison, Koenig, Hays, Eme-Akwari & Pargament, 2001; Pargament, 2002; Pargament, Smith, Koenig & Perez, 1998; Purnell & Andersen, 2009; Roy, 2009; Williams, Jerome, White & Fisher, 2006) and the researcher's professional practice a priori. Coping appeared to be an intricate process that involved behavior and cognition. Coping theorists readily admitted that cognition was not totally understood, though cognitive coping had been conceptualized as a valuable process capable of influencing one's vulnerability to stressful events (Folkman & Moskowitz, 2004). It was believed to include cognitive appraisal and focus related to a problem such as cervical cancer, systematic information processing with judgment in an attempt to take charge while believing that the problem could be solved, and if successful, cognitive adjustment or adaptation occurred (Roy, 2011; Taylor, 1983; Taylor & Stanton, 2007).

Coping additionally was thought to frequently embody a religious dimension, positive or negative (Pargament, 2002; Pargament, Smith, Koenig & Perez, 1998), if religion was accessible from one's background (Hill & Gibson, 2008). Women were known to use religious strategies more often compared to men (Purnell & Andersen,

2009). A religious relevance tended to emerge, particularly when faced with the limits of human capability (Harrison, Koenig, Hays, Eme-Akwari & Pargament, 2001). Moreover, empirical evidence indicated how adjustment to adversity, such as cervical cancer and treatment could be influenced by religious coping (Banthia, Moskowitz, Acree & Folkman, 2007; Pena & Frehill, 1988; Williams, Jerome, White & Fisher, 2006).

A woman's perception, feeling, or belief about her sexual self, defined as sexual self–concept (Andersen & Cyranowski, 1993; Andersen & Hacker, 1983; Garcia, 1999; Holmes, 2002), was believed to be a multidimensional concept (Cleary & Hegarty, 2011; Vickberg & Deaux, 2005) and was an important outcome related to adjustment after cervical cancer treatment (Herzog & Wright, 2007). Only limited research had been conducted related to women's sexual self-concept and the research had primarily been conducted with samples of healthy, young, white, single, undergraduate students (Andersen & Cyranowski, 1994; Garcia, 1999; Vickberg & Deaux, 2005; Wagner & Rehfuss, 2008).

Given the noted gap in the literature, determination of the various factors or stressors from the cervical cancer treatment and the health and demographic variables that were correlated with cervical cancer treatment outcomes, particularly the ability to cope with the disease and treatment related stress and the resultant sexual self concept adaptation was the context for the current study.

Statement of the Problem

All forms of cervical cancer treatment resulted in some degree of physical, psychological and/or sexual sequelae (Andersen, 1989, 1999; Carpenter, Andersen, Fowler & Maxwell, 2010; Herzog & Wright, 2007). Cervical cancer treatment was

stressful and negatively affected women's sexual self-concept and thus, affected women's quality of life (Andersen, 1999). Even though women's sexual concerns and problems after cervical cancer treatment had historically been persistent, identification of women at risk for sexual self-concept problems had rarely been assessed. Nor were the problems that did emerge after cervical cancer treatment assessed or addressed in a systematic manner (Coups & Ostroff, 2005; Katz, 2005; Levin et al. 2010).

Additionally, no studies were found that dealt with coping, cervical cancer and women's sexual self-concept. Therefore, the types of coping strategies to best help women, who struggle with the consequences of cervical cancer treatment and promoted an adaptive sexual self-concept had not been explored and were unknown. Moreover, previous research participants were usually young white, healthy college students who received class credit for participation in the studies (Andersen & Cyranowski, 1994, 1995; Andersen, Woods & Copeland, 1997; Andersen, Woods & Cyranowski, 1994; Vickberg & Deaux, 2005). In addition to more research being needed to understand how to help preserve women's sexual self-concept following cervical cancer treatment, there was also a need for more diverse, community-based samples of cervical cancer survivors to participate in sexual self-concept research. Acknowledging this gap in the existing literature, the purpose of the study was to examine associations among cervical cancer treatment, select demographic variables, coping, and sexual self-concept.

Significance

Today, due to scientific progress there are approximately 11 million cancer survivors (Coups & Ostroff, 2005), many of whom are survivors of cervical cancer. Survivors of cervical cancer, along with newly diagnosed women, must contend with

lingering physical, psychological and sexual sequela after treatment (Ganz, 2001; Jensen et al. 2003). Examination of select variables and their association to women's sexual self-concept could help lead to enhanced treatment and assistance to women who experience these problems after cervical cancer. There are very few interventions that are designed to directly impact women's sexual self-concept. The current study was built upon the groundwork, albeit limited, to help with early identification of women at risk for sexual self-concept problems after cervical cancer treatment. The study could also contribute to the development of interventions, including coping strategies, to maximize women's sexual self-concept and quality of life following cervical cancer treatments. Overall, identification of modifiable factors could help prevent, influence or diminish poor outcomes after cervical cancer and treatment.

Findings from the study could improve understanding and expand knowledge about women's sexual self-concept and the impact of cervical cancer treatment on women's sexual self-concept. Moreover, the study could promote the importance and value of assessing the sexual health of women who experience cervical cancer treatment. A better understanding of sexual health in women following cervical cancer treatment was of great importance, because women frequently contend with the lingering problems in silence (Park, Norris & Bober, 2009; Thaler-DeMers, 2001). Knowledge gained from the study could inform the assessment of women's sexual health and sexual self-concept, as well as, identify a non-adaptive sexual self-concept. Assessment of sexual health is an important standard of nursing care and has been designated as such since 1979 by the American Nurses' Association and the Oncology Nursing Society (Thaler-DeMers, 2001; Wilmoth, 2007).

The current study included an understudied group of women, community-based adult women of all ages, single and married, heterosexual and homosexual compared to the previous participants included in sexual self-concept research (i.e. young, single, white, female undergraduate college students). Voluntary participation from women in many U.S. locations indicated that use of the internet in the current study helped to reach community-based women. Utilizing community-based samples from diverse environments and/or settings help to better understand the impact of cervical cancer treatment and coping on women in general and specifically with women's sexual self-concept. Lastly, the study was a theory-guided research study and findings from the study could inform future research studies related to sexual self-concept and coping after cervical cancer and treatment.

Research Aims

Specifically, the following research aims were examined in this study:

Examine the associations among cervical cancer treatment (e.g. surgery, radiation therapy, chemotherapy and combinations), demographic variables (e.g. time since treatment began, cervical cancer stage, age, health status [perception and number of diseases], socioeconomic status/SES [education and income]), cognitive coping (e.g. focused and processing), and religious coping (e.g. positive and negative) of women who have experienced cervical cancer treatment. Examine the associations among demographic variables (e.g. time since treatment began, cervical cancer stage, age, health status [perception and number of diseases], socioeconomic status/SES [education and income]), cognitive coping (e.g. focused and processing), religious coping (e.g. positive and negative) and sexual self-concept (e.g. sexual-esteem and

sexual satisfaction) of women who have experienced cervical cancer treatment. Examine whether the relationship between religious and cognitive coping and sexual self-concept varies by race and education.

Background

Cervical Cancer

Cervical cell changes are linked to the sexually transmitted human papilloma viruses (HPV), and these changes are responsible for 90% to 95% of all cervical cancers. Transmission of the virus can occur via vaginal, anal, oral or genital-to-genital sexual contact. Condom use can decrease the risk of transmission of HPV, but not eliminate it (Bartlett & Peterson, 2011; Freeman & Wingrove, 2005; Wheeler, 2007). The majority of HPV infections will resolve spontaneously, but persistent HPV infections can be a precursor to the development of cervical cancer (Bartlett & Peterson, 2011). Women tend to experience mutations of persistent HPV infections changing into cervical cancer at or around the peak of their sexually active and family building years (Greenwald & McCorkle, 2007; Herzog & Wright, 2007). However, the mean age for cervical cancer and treatment is 51.4 years and a trend is seen toward "increasing stage with increasing age" (Berek & Hacker, 2000, p. 345). These age associations may suggest that older women are not screened as often as younger women. A delay in screening can lead to a delay in diagnosis and treatment, more advanced disease at diagnosis, and further sexual problems.

Cervical cancer develops slowly over time thus, yielding many opportunities to detect and treat precursor lesions prior to the onset of cancer (Peterson, Murff, Yong, Hargreaves & Fowke, 2008). The changes that begin in the outer cervical area or

ectocervix are referred to as non-invasive cervical cancer (or dysplasia or pre-cancer or carcinoma in situ), related to abnormal tissue development involving the top layer of cells/tissues in the cervix (National Cancer Institute [NCI], 2010; Sevin, 1999). Without treatment the non-invasive cervical cancer will turn into invasive cervical cancer (malignant) and metastasize (spread) via the blood or lymphatic system to seed growth of cancer in deeper layers of cervical cells/tissues, the uterus, organs and locations beyond the uterus. Approximately 80% of the cervical cancers are squamous cell-type and 20% are adenocarcinoma cell-type. Adenocarcinoma subtype is detected less efficiently by the standard screening methodologies (i.e.Papanicolaou test (also called *Pap smear or* Pap test), than the squamous cell type (Waggoner, 2003).

In a simplified manner cervical cancer stages are classified from 0 to IV according to the Federation of Gynecology and Obstetrics staging systems. The stage defines where the disease is located relative to the cervix and beyond. In general, early stage also known as non-invasive cervical cancer was considered stage 0 to stage IIA and IB, and if prognostic factors deemed amendable (i.e. functional/chronological age, histological type, health status/comorbidities), typical treatment may be conization or some form of hysterectomy (type I to III), radiation therapy and chemotherapy. Late stage also known as invasive cervical cancer is considered stage IIB through stage IVB and treatment include hysterectomy; radiation therapy and/or radiation with chemotherapy.

Cervical Cancer Prevention and Screening

Abstinence or HPV vaccines for adolescents and young adults along with cancer screening and HPV tests for adults are the best available preventive measures for cervical cancer at this time. Wide-spread screening in the United States has reduced

invasive cervical cancer incidence rates by approximately 75%, with expectations for continued improvement (Wright, 2007). Condom use can decrease the risk for cervical cancer but not eliminate it (Bartlett & Peterson, 2011; Freeman & Wingrove, 2005; Wheeler, 2007). Despite the success in decreasing the disease, cervical cancer is still a vital cause of cancer morbidity and mortality in women, particularly women without access to health care, in the United States (Bartlett & Peterson, 2011; Wright, 2007).

Even with the advent of the Breast and Cervical Cancer Detection Program (Ward et al., 2004), not all women have the means, will or access to the preventive and early detection measures (Leyden et al., 2005; Sawaya et al., 2001; Schwartz, Crossley-May, Vigneau, Brown & Banerjee, 2003; Wheeler, 2007). There are multiple, sometimes complicated and seemingly interrelated reasons that are reported about why women do not participate in cervical cancer screening; contributing factors include having a history of sexual abuse, having developmental disabilities, obesity, poverty, drug and alcohol addiction, lack of insurance or knowledge about programs that can help procure screening, immigration status, lack of nearby access, penal incarceration, lack of a health care provider, lack of provider recommendation, provider recommendation for cessation of screening due to increased age, provider gender, low acculturation, religious beliefs, lack of knowledge, and embarrassment (Bartlett & Peterson, 2011; Binswanger, Mueller, Clark & Cropsey, 2011; Cadman, Waller, Ashdown-Barr & Szarewski, 2012; Datta et al., 2006; Ferrante et al., 2000; Lantz et al., 2001; Parish, Rose, Luken, Swaine & O'Hare, 2012; Peterson et al. 2008; Schultz, Stava, Beck & Sellin, 2004).

Some women known to have access to health care are not screened, impacting a women's risk for developing cervical cancer. Even women who supposedly had an opportunity to participate in cervical cancer screening, because they were long term members of a health plan with access to the services did not take advantage of the resources Sawaya and colleagues (2001) conducted a retrospective medical record review that included 455 records of women diagnosed with cervical cancer. The women were members of a health plan for 30 to 36 months preceding their diagnosis. It was revealed that half of the 455 women included in the study had not participated in cervical cancer screening within three years prior to diagnosis. It was asserted that the cancer was likely a result of not having been screened in at least three years or more. Older women compared to younger aged women were more likely to lack screening. Additionally, women in the study who did participate in a cytology-based Pap test, follow-up after receiving abnormal Pap results was not found to be a problem and no false positive or negative results were discussed.

Similarly, Leyden et al., (2005) reviewed medical records to examine factors related to women diagnosed with cervical cancer while enrolled in health plans. Over half (56%) of the 833 women in the Leyden study with a diagnosis of cervical cancer had no cervical cancer screening test performed four to 36 months prior to diagnosis, though the women were long term members of health care plans. As in the Sawaya (2001) study, researchers attributed the eventual diagnosis of cervical cancer to the women not participating in cervical cancer screening (Leyden et. Al., 2005). Additional findings in the Leyden study, unlike the Sawaya findings, revealed that 13% of the women diagnosed with cervical cancer were screened prior to diagnosis and failed to

follow-up after receiving abnormal tests results; there was also a failure of the Pap test to detect cervical cancer in 32% of the remaining women in the study, rendering false negative results, possibly indicating a flaw in the sensitivity of the Pap test. Over 80% of the women diagnosed with cervical cancer in the Leyden study had one to three, and sometimes more, primary care outpatient visits during that four to 36 month period prior to diagnosis without participating in cervical cancer screening. Omissions of inquiry about cervical cancer screening or performance of it during primary care visits are missed opportunities that may contribute to the incidence of cervical cancer.

Cervical Cancer Incidence

Despite the difficulties of all women participating in cervical cancer screening, accurate disease detection when screened and treatment, incidence rates of cervical cancer have steadily decreased over time. National incidence rates decreased from 8.3 cases per 100,000 women diagnosed in 1999 to 6.6 cases per 100,000 women diagnosed in 2008 (ACS, 2012). Generally, most cancer incidence rates increase with increasing age (Kennedy, 2000). But cervical cancer tends to affect younger and poorer women more often and the incidence rate peaks between the ages of 30 and 50 years old with the median age being 47 years. The rates then decrease after age 50 in this cohort of women and increase again between the ages of 60 and 69 (American Cancer Society [ACS], 2011; Greimel, Winter, Kapp & Haas, 2009; Sawaya et al. 2001; Vistad, Fossa & Dahl, 2006).

Compared to 60 years ago the current incidence rate is considered remarkably good (Wright, 2007). Nevertheless, women's lives are still imperiled as approximately 4,000 women a year continue to die in the United States from cervical cancer. Wheeler

(2007) and others (Leyden et al. 2005; Sawaya et al. 2001) avow that lack of cervical screening is the most common cause of invasive cervical cancer. The ACS (2012) estimated that 12,170 women will be newly diagnosed with invasive cervical cancer in 2012 and 4,220 women in the United States will die from the disease in the same year.

In summary, cervical *c*ancer survivorship is increasing as a result of improved biomedical science and technology. Cervical cancer, however, remains a problem and it may continue to be due, in part, to the increasing incidence of cancer in an aging population. The ongoing incidence of cervical cancer has a seemingly complicated association to selected individual factors (e.g. age and poverty) and health system issues (e.g. access to and knowledge of care services, inertia of providers). There is a great need to better identify women at risk for cervical cancer, particularly women, who have never been screened or who were not recently screened, regardless of age.

Theoretical Framework

Overview of the Roy Adaptation Model (RAM)

The Roy Adaptation Model (RAM) (Andrews & Roy, 1999; Roy, 2009) provided the framework for the development of the Sexual Health Adaptation (SHA) Theory, the theoretical framework for this research study. Roy developed the RAM based in part from Harry Helson's (1964) Adaptation–level theory, von Bertalanffy's (1969) general systems theory and with significant influence from her mentor and university professor, Dorothy Johnson and others. The model continues to evolve with the help of many practitioners and researchers (Roy, 2009). Only one other study was found to date related to sexual health involving the RAM, of which a middle-range theory was developed and utilized as the conceptual framework for a qualitative study (Stewart,

2010). The assumptions that underpin the RAM are associated with humanism, dignity and mutuality with all human beings. Roy believes that the ability to adapt positively, transforms the environment as well as the adapted individual and ultimately the universe (Andrews & Roy, 1999).

The individual is conceptualized in RAM (Roy, 2009) as a holistic adaptive system interacting constantly with the environment. The conceptual level of the model is divided into three areas: input as stimuli, coping as central control processes, and outcome(s) via adaptive modes. Stimuli input (focal, contextual and residual) come from the environment within and around the individual, somatic and non – somatic, including the offending stressor. Coping mechanisms known as the cognator and regulator make–up the central control processes within the individual relative to adaptation. The coping mechanisms operate with the integration of sensory stimuli into perceptions, which help to connect past experiences with the present and relate to the future. Coping is activated instinctively. Response outcomes to the coping processes are evaluated via four interrelated categories known collectively as adaptive modes and individually as follows: self-concept, role function, interdependence, and physiological. Adaptation is a process and outcome and if adaptive, will promote health, survival, growth and integrity (wholeness). If non-adaptive, a feedback loop reinitiates the coping process. See Figure 1, the Roy Adaptation Model.

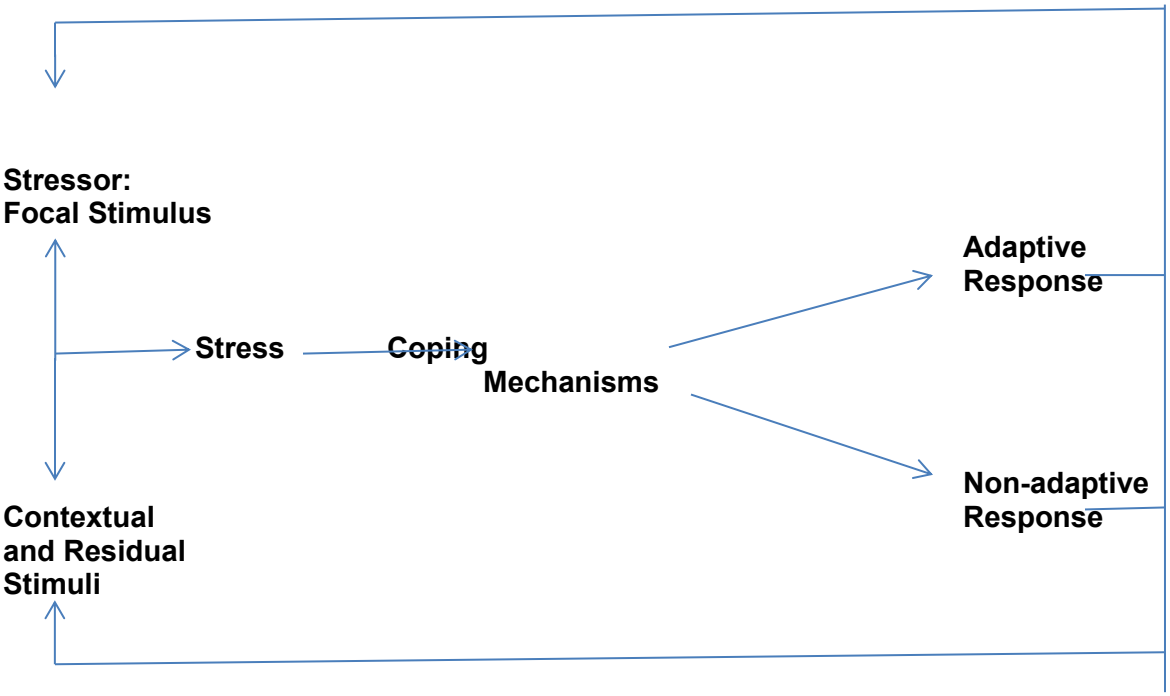
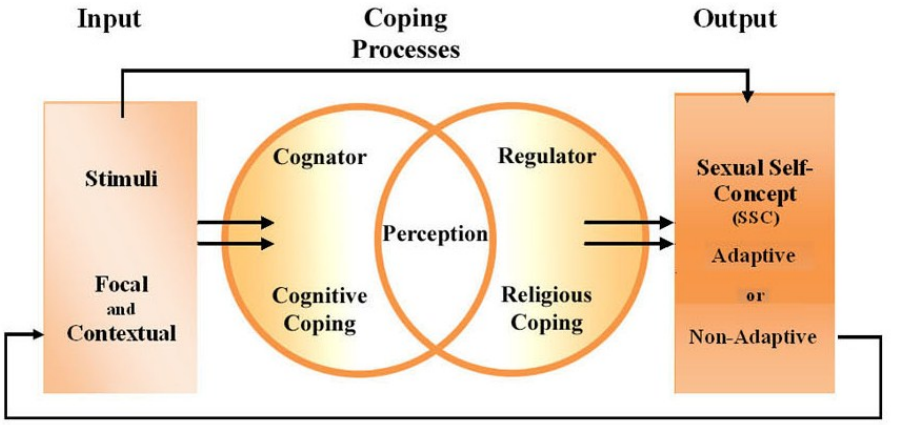


Figure 1. Roy's Adaptation Model (Roy and Roberts, 1981)

Overview of the Sexual Health Adaptation (SHA) Theory

The SHA theory is a middle – range theory that was derived from the RAM (Roy & Andrews, 1999) developed by Hollie, (unpublished manuscript). Figure 2 depicts the SHA Theory diagram.



Focal = cancer treatments
Contextual = demographics

CAP = cognitive adaptation processing involves cognitive and religious coping to help seek meaning and ways of handling/responding to a changing environment in daily and critical situations.

Output = behavior related to adaptive or non-adaptive. sexual – self concept (SSC).

SSC = composite of beliefs and feelings about sexual self.

Figure 2. Sexual Health Adaptation Theory Diagram

Numerous middle-range theories have been conceived from the RAM and have provided frameworks for empirical studies (Boston Based Adaptation in Research in Nursing Society, [BBARNS], 1999). The SHA theory was formulated with the expectation that it would provide a useful theoretical framework to guide sexual health adaptation research. The major assumptions that provided the foundation for the SHA theory are listed below with the nursing metaparadigm concepts represented.

- Sexual health is a vital component of being human and whole.
- Sexual health adaptation results from human and environmental integration.
- Individuals have a fundamental right to have sexual health addressed with overall health.
- Nursing actions maintain or contribute to sexual health adaptation.

The following section will explain in more detail the theoretical concepts of the SHA theory, including stimuli, coping processes and the sexual self – concept adaptation mode. The SHA theory guided the conception of the research aims and hypotheses of the study. *Figure* 3 depicts the SHA theory's conceptual – theoretical substruction model that guided the study.

Figure 3. SHA Theory Substruction

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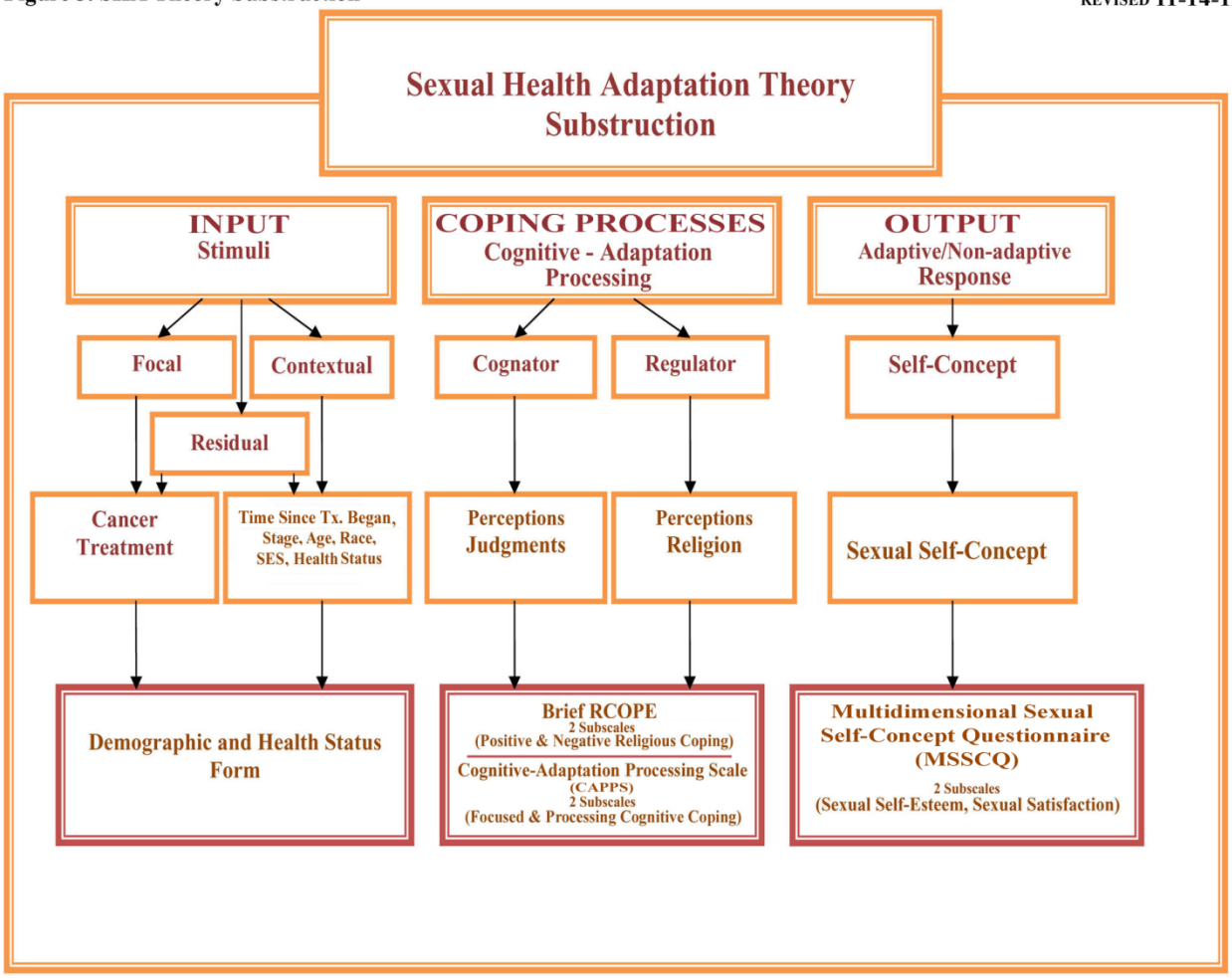

Figure 3. SHA Theory Substruction

Stimuli

Similar to RAM the SHA theory identifies three categories of environmental stimuli: focal, contextual, and residual (Andrews & Roy, 1999; Roy, 2009). All three categories of stimuli coexist in women's internal and external environment and the pooled effect of the three help determine whether women have an adaptive sexual self – concept or non – adaptive sexual self - concept (Roy & Roberts, 1981). A description of each category and its application to this research study follows below.

Focal Stimuli

According to the SHA theory focal stimuli represent the stressor or problem that creates the need for sexual health adaptation (Andrews & Roy, 1999; Roy, 2009; Roy & Roberts, 1981). The focal stressors in the proposed study are cervical cancer treatments: surgery, chemotherapy and radiation therapy. It is well established that sexual problems result from most all of the available treatment options (Greimel, Winter, Kapp & Haas, 2009; Mouga, 2002), and underdiagnosing and underappreciating the sexual problems unfortunately persist (Krebs, 2007; Vistad, Cvancarova, Fossa & Kristensen, 2008). Reactions to stressors can be physical, physiological, psychosocial, or a combination of these and cancer treatments are capable of initiating multiple reactions and more stress (Roy & Roberts, 1981). Sexual health problems seem to be worse when women are treated with radiation therapy alone or in combination with other treatment modalities (Frumovitz et al. 2005). Lastly, since it is difficult to target only the cancer cells for treatment, healthy cells and tissues may also be damaged during treatment (Berek & Hacker, 2000; Greenwald & McCorkle, 2007; Mouga, 2000),

possibly adding to the sexual morbidity burden and increasing the risk for women to be exposed to multiple stressors during one experience.

Contextual Stimuli

Consistent with RAM, contextual stimuli are all stimuli other than the focal stimulus that contribute to the effect (good or bad) of the focal stimulus (Roy & Andrews, 1999). There is an infinite number of factors from women's environments within or outside (internal or external), negative or positive, that may contribute to the behavior triggered by the cancer treatments (focal stimulus) (Roy, 2009). For example it is theorized that contextual stimuli such as one's time since treatment began, cancer stage, age, race, religion, health status, SES and education can impact how women cope during and after cervical cancer treatments. Typically, the contextual stimuli are important because they are tied to the meaning women attach to cervical cancer treatments. The contextual stimuli are often connected to how a person experiences the situation related to the focal stimulus (Roy & Andrews, 1991). An excellent example of this was shown with the finding from a study (De Groot et al., 2005) that revealed how the more time that has passed since cervical treatment began, the less coping was needed. Contextual stimuli (e. g. demographic factors and health status) has also helped to influence outcomes for women with cervical cancer after treatment (Brooks et al., 2000; Hsu et al., 2009).

Residual Stimuli

The last category of internal and/or external environmental stimuli depicted in the SHA theory in accordance with RAM, is residual stimuli. Residual stimuli are unknown speculative factors; that is they are presumed to influence or affect sexual health

adaptation negatively or positively, but are the products of abstract reasoning. An example could be women who may have been sexually abused as a young child and do not remember the event, but have more severe symptomatic sexual problems after cancer treatment than their non-abused cohorts. The influence cannot necessarily be validated. If the speculation is confirmed or validated, it can no longer be considered residual stimuli; instead it becomes contextual or focal stimuli. This transformation from residual to contextual or focal stimuli supports the overall SHA theory proposition that women constantly interact with a changing environment (Roy, 2009). What is a focal stimulus at one time can become contextual and what are contextual stimuli may be forgotten so long that it is possible to become residual stimuli (Roy & Andrews, 1999). Overall, residual stimuli add complexity to the sexual health adaptation process that is not always understood or easily explained.

Coping-Adaptation Processes

According to the SHA theory patterned after RAM (Roy, 2009), the cognator and the regulator subsystems are conceptualized as major coping processes pertaining to adaptation in individuals. The central subsystem processes are complex and dynamic. The central subsystem processes react and/or respond through cognitive channels and an integrated neural system involving coping and cognition (Roy, 2009). Cognition is broadly defined by Roy as the ability to think, feel and act, perceive, reason, judge, make decisions, and cope. Knowledge regarding the precise details of how cognition and coping occurs is limited (Folkman & Moskowitz, 2004; Roy, 2009). Cognitive coping and religious coping seem to reflect the 'goodness of fit' that defines effective

and ineffective coping after experiencing the discord following cervical cancer treatment (Andersen, 1993; Hill & Gibson, 2008; Taylor & Stanton, 2007).

The cognator is theorized to be central to women's cognitive coping processes and the sexual health adaptation process. This subsystem responds through learned ways of coping and interacting with the environment. Included among the learned ways of coping are cognitive channels (Roy, 2009), of which perceptual and information processing with judgment are the most important to this study. Judgment involves decision-making. Perceptual and information processing include activity with perceptions and responses to perceptions. Perceptions are defined as the interpretation of sensory stimuli and help lend meaning to information that is sensed and perceived (Roy & Andrews, 1999). Information processing is done in association with perceptions and other cognitive coping resources and factors, including optimism, mastery/control, education, experience and health status (known as contextual stimuli). Evidence regarding the value of cognitive coping processes in tandem with other variables to help achieve adaptive outcomes has been noted by Stanton & Taylor (2007).

The regulator coping mechanism is the other central coping subsystem and is postulated to be innate, indicating that responses are genetically determined or emerge based on instinct or conditioning (Roy, 2009). In this study, religion is posited to be a part of women's instinctual or conditional experience if there was a religious socialization (Hill & Gibson, 2008), and religious coping emerges when activated (Harrison, Koenig, Hays, Eme-Akwari & Pargament, 2001; Williams, Jerome, White & Fisher, 2006). Positive or negative religious coping is utilized in stressful times to

problem-solve when there is a need to protect, defend, modify or change (Koenig, Pargament & Nielson, 1998; Pargament, 1997). Researchers have reported significant connections between religious coping and health (Harrison, Koenig, Hays, Eme-Akwari & Pargament, 2001; Koenig, 1998; Pargament, Koenig, Tarakeshwar & Hahn, 2004).

Cervical cancer is a sexually transmitted disease and is associated with social stigma (Sevin, 1999), which could support a presumption of negative religious coping among some women. Added influences on women's ability to cope are religious institutions and practices (collectively and individually) that both react and shape women's attitudes (Davidson, Darling & Norton, 1995; Pena & Frehill, 1998; Sevin, 1999; Wagner & Rehfuss, 2008) and affect sexual self-concept. Conversely, in the past there have been recognition of self-protective properties related to stigma e.g. being a member of a strong marginalized group (Crocker & Major, 1989), but such a perspective does not necessarily eliminate damage that may result from social stigma (e.g. poor sexual esteem, poor sexual satisfaction). Nevertheless, positive religious coping and coping resources (e.g. prayers, a feeling of a secure connection to God and others) could be protective for women with cervical cancer (Banthia, Moskowitz, Acree & Folkman, 2007; Pena & Frehill, 1998; Taylor & Stanton, 2007). Negative religious coping have been shown to interfere with adjustment and outcomes, including health outcomes (Pargament, 2002; Pargament, Koenig, Tarakeshwar & Hahn, 2001; Wagner & Rehfuss, 2008

A woman does not have to consciously think about responding in order for the regulator to initiate a response. Furthermore, with the complex interplay of cognition and perceptions as part of the regulator's actions patterned after RAM (Roy, 2009),

women are able to connect past sexual experiences with the present and relate both to future sexual experiences. This process is vital in many ways and acts as a 'regulator' in daily sexual life and critical sexual situations (Andersen, 1999; Andersen & Cyranowski, 1994; Pena & Frehill, 1998; Turner, Center & Kiser, 2004).

Similar to theoretical statements about the self-concept (Markus, 1977), it is conjectured that input (e.g. environmental stimuli also known as focal and contextual stimuli) into both, the regulator and the cognator transform perceptions and the response is seen via an adaptive or non-adaptive sexual self–concept (Helson, 1964; Roy, 2009). If the response is non-adaptive a feedback loop is activated and reinitiates the coping processes and input stimuli move back into the cyclical process. The actual coping processes are not visible however, the outcome is observed via the sexual self–concept. Consistent with the SHA theory based on RAM (Roy, 2009), women are adaptive systems with internal coping mechanisms (e.g. cognator and regulator). Neither the coping mechanisms nor the coping processes are visible, though they are integral to sexual health adaptation.

Adaptive Mode/Sexual Self-Concept

According to the SHA theory the behaviors that result from the work of the coping processes (cognator and regulator mechanisms) are observable via four adaptive modes patterned after the RAM (2009) and inherent in human beings. The four adaptive modes are physiological, role function, interdependence and sexual self – concept modes and behavior responses are observed in all of them. Only sexual self-concept adaptive behavioral responses are relevant to this study.

Just as self-concept is integral to the holism of the person according to Roy (2009), sexual self-concept based upon Roy's self-concept, is conjectured to be basic to women's overall sexual integrity or holism (completeness). Sexual self-concept is a multidimensional concept that embodies several related dimensions (Cleary & Hegarty, 2011; Vickberg & Deaux, 2005), two of which are integral to this study, sexual-esteem and sexual satisfaction (Andersen, 1999; Cleary & Hegarty, 201; Donovan et al 2007; Levin et al. 2010; McCabe & Taleporos, 2003). After experiencing cervical cancer treatment women's sexual self-concept is at risk to be non-adaptive e.g. impaired, affecting women's sexual-esteem and satisfaction (Cleary & Hegarty, 2011; Roy, 2009). Therefore, sexual self-concept in this study was operationalized by sexual-esteem and sexual satisfaction subscales and women's responses via the subscales served as a reference for women to render judgments, decisions, predictions and behaviors about their current and future sexual information.

Definition of Terms

The following terms were defined for use in this study and enhanced clarification of the terms is included in the theoretical framework section. Operational definitions pertinent to the study are provided elsewhere in the paper.

Adaptation – is the process and outcome of individuals (e.g. women) to consciously integrate through perception, thought and behavior with the environment (Roy, 201*1).*

Adaptation-Processing – cognitive patterning of innate and acquired coping behaviors/resources (e.g. mastery/control, optimism, self-esteem, transcendence, growth) to help respond to stressors (Roy, 2011).

Cognator - is a major part of the cognitive coping process and is important for adapting or coping with a changing environment. The cognator is thought to operate through acquired processes known as cognitive channels of which perceptual–information processing (e.g. processes used to develop perceptions about sexual behavior and sexual health; discerning with the help of one's own senses and mind as well as others) and judgment (processes used to make decisions about sexual behavior and sexual health; thinking through the decision systematically step by step) are primary to this study. The cognator process is not visible. It is manifested or carried out through behavior that is usually conscious and learned (Roy & Andrews, 1999).

Cognitive Coping – is the use of thoughts and thought processes to manage, problem-solve and cope (Folkman & Moskowitz, 2004; Roy, 2009; Taylor & Stanton, 2007).

Contextual Stimuli – are all stimuli other than the focal stimulus that contribute to the effect of the focal stimulus (e.g. age, education, health status) (Roy & Andrews, 1999).

Control/Mastery – is able to order, manage, take charge or influence outcome(s) (Taylor & Stanton, 2007).

Coping – behavior and thoughts to manage and problem solve in an effort not to be diminished or harmed during stressful situations (Folkman & Moskowitz, 2004).

Coping Resources – are social and personal characteristics (e.g. optimism, mastery/control, self-esteem, social support) that aid people when coping with stressors (Taylor & Stanton, 2007; Thoits, 1995).

Environment – is the world within and around the person (e.g. relationship, health care provider access) (Andrews & Roy, 1986).

Focal Stimulus – is an internal or external stimulus-stressor to the human system (e.g. cervical cancer treatment) (Roy & Andrews, 1999).

Negative Religious Coping - use of expressions reflecting punishment or impotence of God, feeling of abandonment by God and/or church, spiritual discontent to problem solve and cope (Koenig, Pargament & Neilsen, 1998; Pargament, 1997).

Optimism – expect good rather than bad to happen (Taylor & Stanton, 2007).

Perception(s) – interpretation of sensory stimuli (Roy & Andrews, 1999).

Positive Religious Coping – use of expressions and behaviors reflecting supportive, loving, collaborative, spiritual connections to problem solve and cope (Koenig, Pargament & Nielsen, 1998; Pargament, 1997)

Regulator – is a major part of the cognitive coping process and is an important mechanism for adapting or coping with the changing environment, operates primarily through innate processes (e.g. automatic responses) and through responses commonly known to person/people (e.g. conditioned patterns or responses). The regulator process is not visible. It is manifested or carried out through behavior that usually is not on a conscious level (e.g. use of religion for coping) (Roy & Andrews, 1999).

Religious Coping – use of religion to protect, conserve, transform, problem solve and cope during times of stress (Koenig, Pargament & Nielsen, 1998; Pargament, 1997).

Residual Stimuli –_unknown or speculative factors presumed to influence adaptation Roy & Andrews, 1999).

Sexual Self-Concept - is a perception, feeling, belief about sexual self (Andersen, 1999).

Sexual-Esteem – is one's perception of sexual worth (Snell, 2001).

Sexual Health – is a dynamic physical and psychosocial state and process of being sexually integrated (whole) (Roy & Andrews, 1999).

Sexual Health Adaptation (SHA) – is a dynamic conscious response or adjustment to environmental change in order to be sexually integrated (whole) (Roy & Andrews, 1999).

Sexual Satisfaction - highly satisfied with the sexual aspects of one's life (Snell, 2001).

CHAPTER 2

LITERATURE REVIEW

The literature review will provide a comprehensive and historical overview of the empirical research related to cervical cancer and treatment, select demographic variables, cognitive and religious coping and women's sexual self-concept. The literature review is divided into three sections representing the major concepts in the SHA theory. The first section addresses stimuli also known as input, which includes focal and contextual stimuli that influence women's response to cervical cancer and treatment. This section will discuss and critique an extensive review of cervical cancer treatment (e.g. surgery, radiation therapy and chemotherapy and combinations), demographic variables (e.g. age, race, education, SES, health status) and cancer characteristics (e.g. cancer stage, time since treatment began).

The second section of the literature review consists of a discussion related to the coping-adaptation processes of the theory (e.g. cognitive and religious coping), cognitive coping resources (e.g. optimism and control/mastery) and religious coping resources (e.g. sense of purpose, spiritual connectedness with God and others). Within the theoretical perspective of the SHA theory, coping and use of coping resources are considered the work of the cognator and regulator and are the central processes of the theory.

The third and last section of the literature review pertains to sexual self-concept (e.g. sexual-esteem and sexual satisfaction). From the theoretical framework, sexual self-concept is the output of the SHA theory and is the major factor within the adaptive mode. The review of literature in this section deals with the relations of sexual self-

concept to sexual-esteem and sexual satisfaction, both, of which are dimensions of sexual self-concept. The association of sexual self-concept to cervical cancer treatment and coping is included in the review of literature. Each section contains substantiation for the particular literature included in the review and at the end of each section is an overall summary of the state of the literature and gaps in knowledge about cervical cancer treatment, demographics, coping and sexual self-concept.

Stimuli (Input)

Focal Stimuli: Treatment (Surgery, Radiation, Chemotherapy)

Standard treatment for cervical cancer consists of surgery, chemotherapy, radiation therapy, or a combination of the three options (Vora, 1996). While treatment modalities have essentially remained unchanged, new chemotherapy agents, surgical procedures and radiation approaches have continued to be introduced (Vora, 1996). Despite the progress in cancer treatments, associated side-effects persist and it is well established that sexual problems result from most of the available treatment options (Andersen, 1989; Ganz, Rowland, Desmond, Meyerowitz & Wyatt, 1998; Mouga, 2002). The literature suggests that sexual problems seem to be worse and longer lasting when treatment modalities are combined, particularly with radiation therapy (Frumovitz et al. 2005; Mouga, 2002). Since it is difficult to target only the cancer cells for treatment, healthy cells and surrounding tissues may be damaged during radiation treatment (Berek & Hacker, 2000; Greenwald & McCorkle, 2007; Mouga, 2000) adding to the sexual morbidity burden.

Surgery

The standard surgical treatments for early cervical cancer (e.g. stage I – IIa) include cryosurgery, laser vaporization, Loop Electrosurgical Excision Procedure (LEEP) or a cone biopsy (cone shaped biopsy taken from the cervix), total hysterectomy

(removal of uterus and cervix only, also known as simple hysterectomy), radical hysterectomy (removal of uterus, bilateral ovaries and fallopian tubes, nearby tissues and ligaments removal of upper vagina attached to cervix), and modified radical hysterectomy (partial radical hysterectomy with removal of less tissue and organs compared to a radical hysterectomy). Surgical cancer treatments can range from minimally invasive surgeries (e.g. cryosurgery) to significantly invasive surgery with multiple tissue and organ removal (National Cancer Institute, 2010).

Several less invasive surgical treatment procedures have been introduced within the last decade and are increasingly being utilized: laparoscopic radical hysterectomy, robotic radical hysterectomy, robotically assisted laparoscopic (total) hysterectomy, radical trachelectomy (cervix amputated from the uterus, tissues and upper part of the vagina removed, lymph nodes removed and uterus is attached to remaining vagina), and robot-assisted laparoscopic radical trachelectomy and ovarian transposition (movement of ovaries to preserve fertility before cancer treatment commences). These procedures have helped minimize surgical invasiveness and preserve function and fertility during cervical cancer treatment (Carter, Sonoda, Abu-Rustum, 2007; DeNardis et al. 2008; Huang, Lee, Tsai, Han & Hwang, 2007; Ko, Muto, Berkowitz & Feltmate, 2008; Pareja F., Ramirez, Borrero F. & Angel C., 2008; Persson, Kannisto & Bossmar, 2008; Li et al. 2007). Little information is available regarding what impact the new procedures may have on women's sexual health except for a few documented adverse surgical events (e.g. expulsion of cerclage [suturing uterus shut] with a trachelectomy, post-operative peritonitis, apraxia of quadriceps) (Ko, Muto, Berkowitz & Feltmate, 2008). The small numbers of studies that have been conducted with the new

procedures report promising outcomes, but unfortunately, study participants have been primarily comprised of White middle and upper class educated women (Kirwan et al., 2003). At this time there is not enough long-term clinical trial data on the new procedures to evaluate efficacy, survival, or suitability with more diverse populations or long-term sexual health.

In contrast, standard surgical treatment procedures have been performed for early stage cervical cancer and researched many times, but empirical and anecdotal findings, including findings associated with sexual health concerns, are mixed. Empirical evidence supports that problems related to surgery are often mild, short-term problems, including what some refer to as benign sexual health problems, (Frumovitz et al. 2005; Greenwald & McCorkle, 2008; Greenwald, McCorkle & Fennie, 2008; Grumann, Robertson, Hacker & Sommer, 2001; Jensen et al. 2004). Conversely, other evidence-based support revealed more persistent post-operative problems and long-term sexual health problems (Bergmark, Avall-Lundqvist, Dickman, Henningsohn & Steineck, 1999; Cull et al. 1993; Herzog & Wright, 2007; Pieterse et al. 2006). There is a clear need for more data; especially data from women's perspectives. The empirical literature also lacks a comprehensive view of the impact on women's sexual health from surgical treatment.

Radiation Therapy

The National Cancer Institute (NCI) (2010) describes external and/or internal (intracavitary or brachytherapy) radiation therapies as treatments that use high–energy radiation to eradicate, palliate and/or shrink cancer cells. Radiation therapy is as effective as surgery at eradicating the disease for early stage cervical cancer. For

women with more advanced cervical cancer, radiation combined with chemotherapy is considered the most effective treatment. Both methods of radiation (e.g. external and internal) can be combined or used alone or with chemotherapy or before or after surgery to treat any remaining cancer. Radiation may cause premenopausal women to become menopausal. After radiation therapy the most frequent physiological problem areas for women who are treated for cervical cancer involve the gynecologic tract, the intestines and the bladder (Burns, Costello, Woolley & Davidson, 2007; Vistad, Cvancarova, Fossa & Kristensen, 2008). Radiation also leads to several psychological concerns (e.g. loss of femininity) (Gamel, Hengeveld & Davis, 2000). Radiation was thought to be associated with significantly more sexual dysfunction compared to surgery and chemotherapy (Donovan et al. 2007 p. 432).

According to Andersen (2000) approximately 60% of women with cervical cancer receive radiation therapy and suffer consequential changes to the vagina. External beam and internal implants have long been recognized to cause the most damage to the vaginal mucosa compared to other cervical cancer treatments. Such damage includes vaginal shortening, gradual fibrosis causing tight narrowing and moderate to severe decreased vaginal lubrication resulting in mild to severe dyspareunia, and decreased blood flow and thinning of the vaginal walls, low to no libido and overall sexual dissatisfaction (Andersen, 2000; Bergmark, Avall – Lundqvist, Dickman, Henningsohn & Steineck, 1999, 2002; Frumovitz et al. 2005; Jensen, et al. 2003; Robinson, Faris & Scott, 1999). For some, the problems are more long-term sexual problems and they all interfere with a woman's sexual health and sexual self-concept (Greimel, Winter, Kapp & Haas, 2009; Mouga, 2002). Jensen et al., (2003) reported

problems occurred throughout two years following radiation therapy and the problems persistent with the same intensity throughout that time with little change. Women who received surgery and radiation reported more sexual and vaginal problems. This was also the case with women who received combined external radiation and brachytherapy. They too, reported a great number of difficulties with sexual functioning and sexual satisfaction (Juraskova et al., 2003). Bimodal treatments seemed to result in much more problems for women than single treatment modalities.

Gamel, Hengeveld and Davis (2000) and others (Bruner & Boyd, 1999; Jensen et al., 2003, 2004; Robinson, Faris & Scott, 1999) reported that women who receive radiation therapy experienced added distress brought on by feelings of anxiety and perceptions about loss of femininity. The anxiety is multifaceted, and included fears related to the use of large machines for treatment, being among other very ill women, worry about contamination, and embarrassment related to pelvic exposure during treatment. The researchers also identified that women reported feeling less feminine because of radiation induced changes to their skin, loss of fertility, loss of hair, and permanent body markings (used to enable accurate radiation aim during treatments). Women with partners reported fearing the loss of their partners because of the absence of a sexual relationship. Much of the psychological distress following radiation remained unexpressed (Ganz, 2001; Klee, Thranov & Machin, 2000; Jensen et al., 2003).

A recent study conducted by Vistad, Cvancarova, Fossa & Kristensen, (2008) provided an excellent example of the fallibility of relying only on observational skills, and professional intuition to evaluate important subjective patient information. An important

aim of the study was to compare the results of physicians' assessment of morbidity of cervical cancer survivors (post radiation) to the survivors' self-rated symptoms. The sample included 147 women, who were cervical cancer survivors, who had received standard radiation therapy treatments. A self-report questionnaire was sent to the women and a total of 91 (62%) questionnaires were returned. No significant differences were found between the women who responded and those who did not. The women's self-reports were compared to physicians' assessments involving bladder (urgency, frequency, incontinence, pain or bleeding with urination) intestinal (nausea, vomiting, urgency, frequency, leakage, pain and blood) and vaginal morbidity (pain with intercourse or dryness). Major findings revealed gross discrepancies between the physicians' rating of patient morbidity compared to patients' self-rated-assessments. Physicians estimated patient's distressful symptomatology to be at least 50% less than what patients self-reported as distressful. Comparisons of vaginal problems were eventually dropped because of large proportions of missing physician-assessment data. The prevalence of patient-rated symptoms involving the intestines and bladder was self-reported as much higher among sexually active survivors, possibly because of interference with sexual activity. This study highlighted the importance of asking relevant questions and not assuming or relying on unconfirmed intuition, so the patient's perspective can be used to help resolve problems.

Chemotherapy

While information about sexual problems after the administration of chemotherapy is beginning to be emphasized, there is still a dearth of literature addressing the issue (Rogers & Kristjanson, 2002). Well over a decade ago Kaplan

(1994) made the astute observation that while there are detailed descriptions in the literature about non – sexual side – effects of chemotherapy (e.g. nausea, fatigue, pain, anemia), information regarding sexual side – effects are rarely discussed with the same level of detail. The same observation can be made today, almost 20 years later. The majority of literature about chemotherapy and sexuality involved women with breast cancer and tended to focus on sexual side – effects from adjuvant chemotherapy (Partridge, Burstein & Winer, 2001; Rogers & Kristjanson, 2002, Wilmoth, 2001). Adjuvant chemotherapy is added chemotherapy or some other form of therapy in addition to the standard dose of chemotherapy. Usually higher doses of chemotherapy are used as an adjuvant agent for palliative control during late stage cervical cancer (NCI, 2010). Nevertheless, since a cancer drug is anticipated to have the same reactive properties whenever it is given, it is reasonable to extrapolate that the effects on women with breast cancer would be similar to women with other cancers, such as cervical cancer.

Unfortunately, little is known about the sexual side effects of chemotherapy beyond the anecdotal accounts provided by women. An abundance of literature, including systematic reviews of acute and/or late toxicity problems of chemo-radiation for cervical cancer have been published without mention of sexual side-effects (Cadron, Amant & Vergote, 2005; Kirwan et al. 2003). Since chemotherapy agents potentially affect all tissues in the body, it is reasonable to believe that they would also impact the reproductive system and create sexual health problems for women (Mouga, 2002). Sexual problems connected to chemotherapy that are most often discussed in the literature include chemically induced ovarian failure resulting in infertility and premature

menopause with its associated symptoms (e.g. vaginal dryness, hot flashes, dyspareunia, sleep disturbances) (Mouga, 2002; Rogers, 2001; Wilmoth, 2001). Since chemotherapy is becoming important in the treatment of cervical cancer, and quality of life issues for survivors are becoming equally important, more research and knowledge is needed.

To summarize, the precise extent of sexual problems among cervical cancer patients following the various treatment options remains limited, perhaps because neither patients nor providers readily discuss the problems (Hughes, 2009; Katz, 2005; Meerabeau, 1999; Park, 2009). Empirical evidence indicated that surgery, radiation therapy and chemotherapy are effective treatment options for women with cervical cancer and each are increasingly being used in various combinations to improve survival (Kirwan et al., 2003; Ryn, Chun, Chang, Chang & Lee, 2005). The data also clearly indicated that women have post-treatment difficulties, primarily physical, psychological and sexual morbidity, that occur immediately following most treatments and can last long-term (Greenwald & McCorkle, 2008). Problems may occur later depending on the treatment modality (Gamel, Hengeveld & Davis, 2000). While there is an increasing trend to use multimodal treatments, there is a paucity of data on the long-term effects and quality of life issues related to combined treatment (Kirwan et al. 2003; Maduro, Pras, Willemse & de Vries, 2003). Radiation difficulties are reported to occur as much as two to ten years later or more, after treatment (Gamel, Hengeveld & Davis, 2000; Jensen et al. 2004). Nevertheless, tremendous advances in the treatment of cervical cancer have been made and the efficacies of current preventive measures have been evidenced, though more knowledge regarding treatment and its effect on sexual

health is needed. It is well documented that survival is the primary goal of all cancer treatment, including cervical cancer; however, quality of life, palliation of symptoms and preservation of sexual health is also important to women and worthy of consideration and discussion.

Contextual Stimuli: Age, Race, SES, Cervical Cancer Stage, Health Status, and Time since Treatment Began

Age

Compared to other gynecological cancers, cervical cancer primarily affects middle-aged women at a mean age of approximately 50 years (Greimel, Winter, Kapp & Haas, 2009; Kastritis et al. 2007). Women who have experienced cervical cancer treatment and cure have an added life expectancy, well over 20 years after treatment. Thus, the women may have to endure the physical and psychological impairment related to the disease and treatment for many years (Bergmark et al., 1999; Jensen et al., 2003; Vistad, Fossa & Dahl, 2006). The precise role that age plays related to cervical cancer has not been well studied, though age is repeatedly discussed with other pertinent demographics associated with cervical cancer. There were no studies found that identified an independent association between age and cervical cancer; rather age was more often associated with disease stage (Schwartz, Crossley-May, Vigneau, Brown, & Banerjee, 2003) and survival (Kastritis et al. 2007). The relationship between age and stage of the disease was often discussed relative to screening deficiencies and inadequate follow-up after screening, particularly among older women (Leyden et al. 2005; Sawaya et al. 2001; Wright, 2007). It appeared that age as a

contextual stimulus is complicated by screening issues and treatment follow up deficiencies in older women.

Even though no independent association was found, increased age has been well documented as an important factor associated with poor survival after diagnosis of cervical cancer (Coker, Du, Fang & Eggleston, 2006; Howell, Chen & Concato, 1999; Merrill, Merrill & Mayer, 2000; Shelton, Paturzo, Flannery & Gregorio, 1992; Wright et al. 2005). Many studies indicated that women 65 years of age and older presented more frequently with advanced stages of cervical cancer and were more likely to die from the disease compared to younger women. The Coker study proffered that increasing age was consistently associated with poor survival and if older women had equal access to medical care, (e.g. Medicare insurance), the usual predictors of poor survival (e.g. SES, race/ethnicity) would have less of an impact on survival. The Coker team findings further suggested that the effects of comorbidity and treatment could adversely impact survival of older women even with equal access. The Wright team's and the Merrill group's findings appeared to agree with the Coker group's results regarding the problems caused by age and comorbidities. Both, the Merrill and Wright groups discussed how moderate to severe comorbidities commonly seen with the elderly were likely to influence the care process for older women, including treatment decisions made by physicians and the women with cervical cancer. The above issues (e.g. advanced stage, the impact of SES, comorbidities) were all important matters and they affected the survival outcomes for women. The remaining studies conducted by Howell, Chen & Concato, (1999) and the Shelton (1992) researchers uncovered similar findings that

suggested how and when advanced age affected survival of women with cervical cancer.

Younger women, approximately 45 years or below, particularly with advanced disease were at a greater risk of death also (Delaloye, Pampallona, Coucke & De Grandi, 1996); though, not all studies suggested an association between younger age and poor survival. After controlling for stage, race, SES and health status, several studies found that age was not associated with poorer survival (Brooks, Baquet, Gardner, Moses & Ghosh, 2000b; Meanwell et al., 1988; Sawaya et al. 2001) Overall, the association between age and poor survival was mixed and complicated by other contextual stimuli (e.g. stage, SES, health status).

Regardless of the mixed findings between age and survival, age was undeniably a strong factor in the selection and allocation of treatment for women with cervical cancer. Less aggressive treatment, no treatment at all and lack of participation in clinical trials were widespread practices applied with older women who had cervical cancer (Chapman, 1992; Kennedy, 2000; Kastritis et al. 2007; Merrill, Merrill & Mayer, 2000; Wright et al. 2005). Many of the practices were noted in a study about survival rates in women 65 years and older, who were diagnosed between 1951 and 1985 (Chapman, 1992); survival was concluded to be poor. Then and now, the same practices continue with little empirical evidence to support their use (Wright et al. 2005).

A well documented age-related issue in cervical cancer research was frequent experiences of distress during the disease and treatment and post-treatment phase among younger women compared to older women (Bergmark, Avall-Lundqvist,Dickman, Henningsohn & Steineck, 2002; Carpenter, Andersen, Fowler &

Maxwell, 2009; Wenzel et al., 2005). The Bergmark et al., (2002) study examined 256 women who reported distress related to specific symptoms after cervical cancer treatment. Among the study findings it was revealed that women's distress differed by age. Interestingly, an age gradient emerged in a direction that indicated that older women were less distressed than younger women. The same age-related phenomenon was shown when Carpenter and colleagues (2009) conducted a study to test sexual self-schema with sexual functioning and body-change stress after cancer treatment. Demographic variables were examined to determine whether younger women compared to older women would report more distress related to sexual and psychological outcomes. The findings showed that not only did younger women report more sexual and psychological distress; they also reported experiencing higher levels of intrusive thoughts (possibly related to their perceptions or fears about sexual activity or recurrent cancer) and avoidance with regard to their bodies (possibly related to looking at their body or perceptions related to others looking at their body).

Another study (Wenzel et al., 2005) conducted with a unique sample of long-term cervical cancer survivors of childbearing age found that younger aged survivors expressed greater distress compared to the oldest survivors of childbearing age. Most of the women were diagnosed five to ten years earlier before the study, though their distressful concerns persisted at the time of the study. The women were at a mean age of 45 years at the time of the study and reported enjoying good quality of life despite their concerns, some of which centered on reproductive issues. It was not reported whether the women discussed their concerns with any professional at the time of diagnosis or after treatment.

Evidence of this age-related reaction was not unique to cervical cancer patients. A study conducted by Kornblith et al., (2007) found a similar age-related reaction with breast and endometrial cancer survivors. The study specifically tested whether there were adjustment differences between younger and older women. Results showed that differences were indeed present and younger women reported significantly worse adaptation than older women. This difference also emerged with additional measures involving psychological state, cancer treatment, sexual problems, stressful life events and help needed for unmet needs.

The phenomenon of younger women experiencing greater distress during and after cancer and treatment appeared to be a general finding in cancer research. However, there were mixed results, including no differences or certain distress reported by younger women and other types of distress reported by older women (Schroevers, Ranchor & Sanderman, 2004). There are also contrary findings (Schnoll, Harlow, Stolbach & Brandt, 1998) with younger-aged women reporting less distress compared to older-aged women. Nevertheless, all studies helped to identify age as an important demographic characteristic associated with how well women adjusted to cervical cancer and treatment. Moreover, given that cancer and treatment is a life threatening event, poor adjustment to it by women at any age would seem understandable, particularly among women with minimal experience utilizing coping strategies (Diehl, Coyle & Labouvie-Vief, 1996) with no opportunities extended to discuss their distress. It is also understandable that older women with more advanced disease might be less likely to display optimism or a fighting spirit if grossly uncomfortable, fatigued and debilitated. Additional complications with psychological adjustment and sexual matters also suffers

due to the usual pattern of relegating sexual issues to the sidelines or margins of medical care for most patients, especially older women (Lindau, Gavrilova & Anderson, 2007). Shared discussions and decisions between providers and patients could eliminate or attenuate some of the unnecessary complications with women's adjustment. Additionally, more exploration could determine or verify associations among age, medical characteristics, coping and sexual self-concept. It might also provide insight as to how best to help women of all ages adjust after cervical cancer and treatment.

Race

Racial differences were observed in the literature regarding women who have benefitted from cervical cancer treatment progress compared to those who have not. However, the information was not always presented in a clear and understandable manner. Cervical cancer epidemiological data evidenced disparity issues that were confusing and many times conflicting (Mitchell & McCormack, 1997). For example, higher rates of incidence of cervical cancer have been documented among Black women compared to White women, despite reportedly higher screening rates among Black women (Corbie-Smith, Flagg, Doyle & O'Brien, 2002; Merrill, Merrill & Mayer, 2000; Mitchell & McCormack, 1997; Peterson et al., 2008;). Confusing results were also noted between July of 1991 and March of 1998 in the National Breast and Cervical Cancer Early Detection Program data as reported by Benard, Lee, Piper & Richardson (2001). American Indian and Alaskan Native women had the highest and Black women the second highest, abnormal Pap test results. However, White women had the highest biopsy-confirmed high-grade cervical dysplasia. The differences in Pap test and biopsy

results did not appear to be explainable by the numbers of follow-up diagnostic evaluations for women with high-grade cervical lesions or cervical cancer. White women however, had lower numbers of high-grade lesions.

Regardless of the screening and detection problems of racial minorities, there was still an overall decrease in the incidence rate of invasive cervical cancer across all ethnic groups (Erwin et al., 2007). Yet, in the midst of success in eradicating the disease, racial/ethnic issues were frequently documented in association with poor cervical cancer survival (Brooks et al., 2000b; Eggleston et al., 2006; Farley et al., 2001; Morgan et al., 1996). Yet, there remains conflicting data about the associations between race/ethnicity and disease. Some evidence indicated that decreased cervical cancer screening rates and limited access to health care services for both Black and Hispanic women were associated with increased morbidity and mortality rates (Erwin et al., 2007). There was also data to the contrary (Farley et al., 2001; Gorey et al., 1997; Peterson, Murff, Cui, Hargreaves & Fowke, 2008). For instance, in some locations and situations Black women were documented as receiving the most cervical cancer screening (Peterson et al., 2008). Additionally, when equal care was received by minority women and compared to non-minority women, equal outcomes were noted (Gorey et al., 1997; Farley et al., 2001).

Newmann and Garner (2005) addressed race as an important part of a cervical cancer continuum along with other social inequities and illuminated some of the research findings that seemed to confound race as a predictor of survival. For example, in some instances race was considered an independent predictor of survival (Eggleston et al., 2006), even while controlling for various clinical and demographic variables (i.e.

age, race, stage, histology, tumor grade, and if deceased, cause of death) (Brewster et al., 1999; Howell, Chen & Concato,1999). Juxtaposed to these findings, the Morgan et al., (1996) study found that while survival was significantly worse for Black women over 65 years of age compared to White women of the same age, race was not an independent predictor of survival. In fact, when additional clinical and demographic variables were included in the analysis with race (i.e. age, stage, site of disease, insurance status-private/public, date of diagnosis and date of death), race as a predictor diminished considerably. Several other studies (Brooks et al., 2000a; Brooks et al., 2000b; Mundt et al., 1998; Shelton, Paturzo, Flannery & Gregorio, 1992) revealed similar findings. In both of the studies by Brooks and colleagues (2000a & 2000b) involving Black and White women, other variables, particularly co-morbid illnesses and complications from cervical cancer and treatment proved to be as important as race/ethnicity in its impact on survival. The primary focus of the Mundt and colleagues (1998) study was a comparison of Black and White women's tumor characteristics and their responses to treatment (i.e. bleeding and subsequent low hemoglobin). After controlling for differences related to treatment (external and intracavitary radiation therapy and radiation therapy with chemotherapy) and tumor characteristics (adenocarcinoma, squamous cell carcinoma, adeno-sqaumous), race was not an independent prognostic of survival. Early studies, like those of Shelton and colleagues (1992) found associations between race/ethnicity and poor survival to be less clear and quite entangled with other important variables, particularly invasive and non-invasive stages of cervical cancer.

Farley and colleagues (2001) suggested that in an environment with equal access and a reportedly unbiased, nonracial environment, such as in the military health care system, race/ethnicity were not predictive of cervical cancer survival. Yet, racial differences in survival were revealed when a retrospective record review was conducted with over 1500 patients from the Tumor Registry for the United States Military Health Care System. White women (n=1010) were compared with all minority women (African Americans n=158, Filipino n=119, Korean n=60, other minorities n=157, unknown ethnicity n=49). Most of the non-African American minority women were primarily from the Army Medical Center of the Pacific Islands in Hawaii. The Pacific Islands had no organized health care or cervical cancer screening system and 41% of the minority women from there had advanced stage disease. Only 30% of the White women had advanced disease. The women were patients of the military medical center as a result of an agreement made by the U.S. government to provide health care for citizens related to nuclear testing conducted on the Islands in the past. Significant racial differences were revealed in both, five and 10 year survival rates. No differences in the five and 10 year survival rates emerged between White women and all the remaining minority women when women from the Pacific Islands were excluded. The study indicated that with equal care there can be equal survival and early detection.

Despite the racial disparities that result from unequal care, there is continued growth in cervical cancer survivorship across all racial and ethnic categories (Aziz & Rowland, 2002; Schultz, Stava, Beck & Vassilopoulou-Sellin, 2004). Successful cervical cancer survivorship relies on continued improvement in patient and provider

prevention and treatment practices, including effective communication about the impact of the disease (Park, Norris & Bober, 2009; Wheeler, 2007).

Another prevalent concern in cervical cancer research beyond epidemiological studies is greater representation of minorities in all aspects of research (Wendler et al., 2006), such as cervical cancer clinical trials. The inclusion of more women of diverse racial and ethnic backgrounds would inform practice, ensure generalizability of research results and perhaps impact cervical cancer disparities. Few studies sought to understand racial differences among women with cervical cancer and their coping; minority women have rarely been the focus of studies of coping with sexual morbidity and psychological adjustment (i.e. adaptive sexual self-concept) after cervical cancer treatment (Carpenter, Andersen, Fowler & Maxwell, 2009; Cleary & Hegarty, 2011).

The literature has offered threads of evidence suggesting that Black women report less distress compared to Hispanic, Asian and White women during and after cancer treatments (Culver, Arena, Antoni & Carver, 2002; Deimling et al., 2006; Ganz et al., 2003). There were also inferences of greater sexual-esteem/self-esteem (Cleary & Hegarty, 2011; Twenge & Crocker, 2002) and sexual satisfaction among Black women (Ganz et al., 1999) compared to women of other racial groups. As might be expected there were also contrary findings in the literature that provided glimmers of poorer psychosocial adjustment among minority women compared to White women (Ashing-Giwa, Ganz & Petersen, 1999; Bourjolly, Kerson & Nuamah, 1999). These studies suggested more adjustment difficulties for Black women and the problems appeared to have greater associations to a women's SES position rather than race. These studies provided some knowledge, but due to questions that remain related to

conflicting and confusing findings, there is justification for further research using race as a contextual variable impacting cervical cancer and treatment. Moreover, research deficits exists in our understanding of all women's ability to endure and cope with physical, psychosocial and psychosexual sequalae that accompanies cervical cancer survivorship and particularly among minority women (Bergmark et al., 2002; Levin et al., 2010). Additional research findings could help to provide additional knowledge related to all women and race and cervical cancer and treatment. Overall, current findings provided rationale for further exploration of associations among race, coping and women's sexual self-concept.

Socioeconomic status (SES)

Socioeconomic status (SES) is a reflection of one's social position, and is based on one's income, education, and occupation (Singh, Miller, Hankey & Edwards, 2004). In the current study SES is reflected as education and income. The independent impact of SES on cervical cancer has historically been elusive (Shelton, Paturzo, Flannery & Gregorio, 1992; Newman & Garner, 2005). Socioeconomic status and its association to cervical cancer is intricately entangled with other important variables (i.e. age, stage, race/ethnicity) and subsequently difficult to elucidate and the empirical findings are conflicting. Studies are frequently conducted utilizing data from the cancer registries and some of the conflicts are related to the difficulty in monitoring and quantifying SES and inconsistent measurement of SES across studies. Information is not collected on income and education or other SES markers by the National SEER cancer registry or any other cancer registries (Lantz et al., 2006).

To derive SES patterns some studies, such as those conducted by Singh and colleagues (2004) and Schwartz and colleagues (2003) have used an intricate procedure to link information on residential location collected on cancer cases to create a measure of SES. This is accomplished by linking census-based measures, poverty rates and percentage of high school graduates to U.S. mortality data and to the incidence SEER cancer registries of the patient with cancer at the time of diagnosis. Poverty rates correlate highly with SES measures, such as low education level, unemployment rate and occupational composition. The correlation seems to stimulate a somewhat symbiotic effect; each factor makes the effect of the other better or worse. One or more of the measures are included in the procedure to operationalize the SES variable (Singh, Miller, Hankey & Edwards, 2004). These measures are not perfect proxies for individual SES data, particularly since it is assumed that the average SES status of the area is representative of the status of the individual. Furthermore, census data is only collected every 10 years. Several researchers have examined the validity of using census derived SES data and the results have been consistent (Schwartz et al., 2003), but it is not infallible.

Notwithstanding the above, cervical cancer studies have found that many differences attenuate when measures of SES are included in the analysis (Brooks et al., 2000b; Schwartz et al., 2003), illuminating its importance. There were a plethora of study findings that illustrated the importance of an association of lowered SES (low income, low education level) to poor cervical cancer survival, treatment, health status, and other variables (Brooks et al., 2000b; Gorey et al., 1997; Franco, Duarte-Franco &

Ferenczy, 2001; Woods, Rachet & Coleman, 2006). In the Brooks et al., study, race and comorbid illnesses with SES were associated with poor survival.

The Gorey and colleagues' study (1997) compared whether SES made a difference on the survival rate related to cervical cancer along with several other common types of cancer in Toronto, Ontario to the survival rate in Detroit, Michigan. The effect of SES on Toronto's cancer survival rate, with its universal access to health care, was compared to the effect of SES on the cancer survival rate in Detroit, Michigan, where there is not universal access to health care. Not only was there a consistent pattern of survival advantage observed in Toronto, no association was observed between SES and income measured by community areas related to residence. Additionally and unexpectedly, there was a survival increase beyond the usual survival rates among the Canadian participants. Survival rates in Detroit, Michigan were significantly (at the 95% confidence interval) poorer among people from lower SES measured by community areas related to residence.

Franco, Duarte-Franco & Ferenczy, (2001) provided a cogent ecological treatise on the history of cervical cancer relevant to the Americas and Canada. Basically incidence and mortality declined in North America and Canada during the last 50 years and there was substantial progress in understanding and knowledge about the natural history of cervical cancer and treatment. Women in developing countries, Central and South America, southern and eastern Africa and the Caribbean and American and Canadian Aboriginal were among those with the highest mortality rate. Lastly, a review of research studies from 1995 to 2005 detailing with cancer survival rates, including cervical cancer, related to the impact of SES was completed in 2006 by Woods, Rachet

& Coleman. These studies contrasted sharply to the results revealed by Coker and colleagues (2006) when SES and cervical cancer survival among older women was investigated. The Coker team found that neither race/ethnicity nor SES was associated with poor cervical cancer survival among older women with Medicare insurance after being diagnosed with cervical cancer. Instead, increasing age and not SES was found to be associated with poor survival across several studies (Bradley, Given & Roberts, 2004; Coker et al.; Farley et al., 2001; Howell, Chen & Concato, 1999; Morgan et al., 1996;Sawaya et al., 2001). Even after controlling for age, race and stage, SES was still not associated with survival and the results after these adjustments were consistent with an earlier study (Shelton, Paturzo, Flannery & Gregorio, 1992).

In contrast, Eggleston (2006) and colleagues, including Coker, who took part in the study, showed that lower SES (low income, education, occupation) was associated with decreased survival among minority women (Black and Hispanic) diagnosed at later disease stages. Yet, the majority of the women in the study was reportedly diagnosed in early stages of the disease and was of White, non-Hispanic descent. Hispanic women in the study were more likely than White, non-Hispanic women to be diagnosed at a later stage, but less likely to die of the disease. Though, it was not made clear if Hispanic women were less likely to die compared to White women or Black women or both. The association between lower SES and poorer survival was stable across all racial groups, suggesting that SES was possibly more important than race in the results.

The findings by Eggleston and colleagues were consistent with findings from a number of other studies (Morgan et al., 1996; Mundt et al., 1998; Singh et al., 2004). Though the Morgan et al., study included women with cervical, uterine and ovarian

cancer, only Black women with cervical cancer were more likely to have advanced disease and significantly poorer survival as shown by the log-rank survival test. While Black women were overall, significantly worse than white women, race was not an independent predictor of survival. The findings were similar in the Mundt et al., study, but the difference in survival did not reach statistical significance. The Singh et al. study found that poor survival increased with increasing poverty for women in all racial groups.

Consistent empirical evidence showed that a lowered SES influenced morbidity and mortality directly or indirectly (Brooks et al., 2000b; Gorey et al., 1997; Morgan et al . Schwartz et al., 2003; Singh et al., 2004). There was no doubt that in some studies SES clearly influenced morbidity and mortality. Moreover, if equal access to care was accounted for, improved survival was often achieved. In fact, the federal and state funded program, the National Breast and Cervical Cancer Early Detection Program (known in Michigan as the Breast and Cervical Cancer Control Program) was created specifically to correct this public health concern. The program's objective was to help eliminate the unequal burden of cervical and breast cancer and provide equity in access, care and cost to low-income, uninsured women (Ward et al., 2004).

As noted above, there were pathways that linked low SES with morbidity and mortality in poor women who have experienced cervical cancer treatment, particularly poor minority women, (Eggleston et al., 2006; Morgan et al., 1996; Mundt et al., 1998; Singh et al., 2004). The causation of the linkage was often debated and at times, controversial. Adler & Snibbe, (2003) posited that there is a gradient between SES and health. People in all social classes are positioned on the gradient according to their

SES, specifically their income, education and health. The lower a person's SES, the lower their position is on the gradient. Stress is frequently documented as a part of a low SES position (Banthia, Moskowitz, Acree & Folkman, 2007; Baum, Garofalo & Yali, 1999). It is also an important part of women's cervical cancer experience and related to their position if poor, on the SES-health gradient (Bergmark et al., 2002; Carpenter, Andersen, Fowler & Maxwell, 2009). How SES operates in combination with other demographic variables of women who have experienced cervical cancer and treatment remains mixed and an important area for continued research. Determining if coping strategies might provide a mediating pathway to buffer some of the stress for low SES women (and particularly lower SES minority women) is equally if not more important to explore (Costanzo, Lutgendorf, Rothrock & Anderson, 2006; Deimling et al., 2006; Williams, Jerome, White & Fisher, 2006).

Cervical Cancer Stage

Cancer staging is an important prognostic indicator for cervical cancer (Waggoner, 2003) and treatment is predicated on the stage of the cancer. Staging has historically been employed to predict disease outcomes, determine treatment options, and guide information given about symptoms, prognosis, and likelihood of recurrence and disease free survival actuaries or projections (Han et al. 1999; Ho et al., 2004; Waggoner, 2003). Cervical cancer disease stage also predicts survival and appears to be a better predictor of outcomes, despite the conflicting age and race/ethnicity data.

A wealth of evidence indicated that older women were continually diagnosed at a later, more advanced cervical cancer stage compared to younger women (Brooks et al., 2000b; Brun et al., 2003; Chapman, 1992; Ferrante et al., 2000; Schwartz et al., 2003;

Shelton, Paturzo, Flannery & Gregorio, 1992). Moreover, older Black women were more likely than older White women to be diagnosed at a later (advanced) stage or not to have their cervical cancer staged at all (Mandelblatt, 1991; Merrill, Merrill, Mayer, 2000; Sawaya et al., 2001). In addition to often being diagnosed with late-stage invasive cervical cancer, the Sawaya study demonstrated that older women were more likely to die from the disease. However, death seemed to be more closely associated with having an advanced stage of invasive cervical cancer. Similarly, findings from the Shelton and colleagues' (1992) study several years earlier, found that survival was significantly related to the stage of disease. After controlling for age, race and SES, Shelton found that women with invasive disease were 11 times more likely to die from the disease compared to women with non-invasive disease and this result was found to be significantly influenced by race and age.

Interestingly, survival between Black and White women with advanced cervical cancer was equivalent in the study conducted by Brooks and colleagues (2000b). The objective of that study was to evaluate associations among stage, clinical and socio-demographic characteristics in patients with invasive cervical cancer. Black women were more likely to be diagnosed with an advanced stage of invasive disease (stage II to IV) compared to White women. Yet, in this same study when survival was adjusted for race, Black race was associated with significantly lower survival for Black women diagnosed with early stage disease (stage I to II). The rationale offered for this result was that it might be reflective of a higher tendency for White women to have smaller tumors (stage IA-IB) compared to Black women or there were differences in treatment not known by the researchers or not detected during the study.

Lastly, a study (Schwartz et al., 2003) was conducted in the Metropolitan Detroit area that investigated associations among invasive cancer stages to sociodemographic variables (e.g. SES, race) among Black and White adults. While the study included other cancer cases, the 966 cervical cancer cases were the primary interest and whether race or SES or both would independently predict racial differences in stage at diagnosis. It was found that for all cancer cases, most importantly the cervical cancer cases, SES was an independent predictor of stage, indicating that the cases from the lowest SES group were significantly more likely to be diagnosed with advanced stage disease. Age was also an independent predictor of stage at diagnosis for all the cervical cancer cases and older women were more likely to have advanced invasive cervical cancer diagnosed compared to younger women. However, for cervical cancer after controlling for SES differences, race did not predict stage.

Health Status

Empirical evidence suggested that assessment of perceived health status and comorbidities is an important prognostic factor for people with cancer and it is particularly important for women with cervical cancer and after treatment (Denton, 2008; Lantz et al., 2001; Waggoner, 2003). Health status appeared to contribute to cervical cancer outcomes in two important ways: comorbid conditions complicated or aggravated the disease process and perceived health status altered psychological adjustment. Findings from the Brooks and colleagues study (2000b) raised the issue of whether health status, screening and follow-up care contributed to survival rates (Farley, et al., 2001). Regression analysis was performed in the Brooks' study and in

the final regression model; stage III-IV, comorbid conditions/illnesses and black race were associated with poor survival, even after controlling for stage of disease.

These prognostic factors are especially important for Black women with low SES, because they report more acute life events (e.g. on-going discrimination experiences as documented by Schultz et al., 2000), and have more complicated conditions that may compromise treatment and survival (Howell, Chen & Concato, 1999). Comorbid conditions and illnesses (e.g. diabetes, hypertension, intravenous drug and alcohol use or abuse, circulatory disorders, pulmonary disorders, neurological disorders, HIV infection) were found more frequently associated to Black women compared to White women, but without statistical significance. Additionally, increasing numbers of comorbid illnesses have been empirically correlated with decreasing participation in cervical screening, which could result in unnecessary diagnoses of cervical cancer at more advanced stages (Hicks, Yap, Matthews & Parham, 2006).

Evidence further suggested that poorer prognosis for invasive cervical cancer in elderly women may be more influenced by comorbidity (hypertension, diabetes, chronic, and respiratory diseases) and tumor stage than by treatment efficacy. The associations were thought to be obvious in a case control study (Brun et al., 2003) comparing 62 women over 65 years of age to 124 women less than 50 years of age. Minor and major comorbidities were significantly higher and hospital stay was longer in the older women. However, interestingly intraoperative and postoperative complications were not significantly different.

Health status assessment in the current study served as an ordinal level variable that measured women's self-rated global, subjective perception of their current health

status as excellent, very good, good, fair or poor (Hsu et al., 2009). A self-report of the current number of comorbidities served as the objective portion of the health status assessment. Moreover, the global self-rating of health status provided a simple, direct and global way of capturing perceptions of health and was economically feasible. Women's perception of health status after cervical cancer treatment was an essential addition to what were usually the traditional indicators in the assessment of health. It also demonstrated the relevance of incorporating women's perspectives, which has usually been overlooked (Ganz, 2001; Horden, 2008). The association between 'objective' and 'subjective' health status has previously been viewed as a methodological problem (Hunt, McEwen & McKenna, 1985). More recently self-reported information (e. g. comorbidities) has been shown to have a high predictability of mortality and links to other health outcomes (Brooks et al., 2000b; Hsu et al., 2009). Along with this, self-rated health status is known to have high test-retest reliability (Lantz et al., 2001). The evidence justified including health status assessment with a subjective and objective aspect in the current study despite suggestion of methodological problems.

Time Since Treatment Began

'Time since treatment began' essentially is time that passed since treatment was started for women with cervical cancer. Limited empirical evidence suggested that with a notable increase in 'time since treatment began', there could be a significant decrease in the distress that permeate women's concerns with cervical cancer treatment (Bourjolly, Kerson & Numah, 1999; Culver, Arena, Antoni & Carver, 2002; De Groot et al., 2005; Barnas, Skret-Magiero, Skret & Bidzinski, 2012) It was conjectured that

along with this change there could be other significant differences, particularly as guided by the coping-process component of the SHA Theory.

For people who have cancer, 'time since treatment began' demarcates all that follows in their lives after cancer is diagnosed and treatment began (Ganz, 2001). Their lives are fundamentally changed. Additionally, when the disease is not cured, but instead controlled for extended periods of time, the 'time since treatment began' becomes even more valuable (Ganz, 2001). This is particularly true for women and their families, who have survived cervical cancer and treatment. An example of this was seen in the study conducted by the De Groot (2005) team and provided empirical support for the 'time since treatment began' variable in the current study. The De Groot study assessed the range and intensity of concerns experienced by women with invasive cervical cancer, stage I-IV, up to two years since treatment began and included their male partners. The participants completed the Cervical Cancer Concerns Questionnaire and reported equal intensities of concern. The Intensity of concerns differed with the stage of the women's cancer and the amount of 'time since treatment began'. Women reported lower intensities of concern when they had earlier stage disease (stage I-IIA) and were a year or more out from the 'time since treatment began'. Research findings similar to the De Groot study have also been seen among women, who had breast cancer (Culver, Arena, Antoni & Carver, 2002).

Since treatment of cervical cancer markedly improved and women are living longer, there is an increasing focus on quality of life after treatment. The time after treatment is an important part of women's survival. Maher & Denton (2008) discussed survival as consisting of three stages: the acute survival stage, the extended survival

stage and the permanent long-term survival stage. Throughout all the stages after cervical cancer treatment, women have reported experiencing different degrees of physical, psychological and psychosexual problems (Basen-Engquist et al., 2003; Ganz, 2001; Greenwald, McCorkle & Fennie, 2008; Jensen, 2003). However, it is well documented that women who had cervical cancer and treatment report more difficulty after treatment and for longer periods of time compared to women with other gynecologic cancers and breast cancer (Herzog & Wright, 2007). An example of this comparison was clearly depicted in a study conducted by Eisemann & Lalos (1999), who assessed well-being in women with endometrial and cervical cancer at three time intervals: pre-treatment, six months post-treatment and one year post-treatment. Results indicated that compared to the endometrial cancer survivors, the women with cervical cancer reported significantly more symptoms at all time periods.

Conflicting accounts of the amount and length of difficulty after treatment is not unusual. For example, in a study conducted by Greimel et al., (2002), which assessed women with breast cancer and several types of gynecologic cancer, including 79 women with cervical cancer, compared aspects of quality of life at six time intervals (pre to one year post-treatment) and revealed some of the variance that exist. There were no statistical differences among the women on any quality of life domains at the pre-treatment time interval. Breast cancer patients compared to cervical cancer patients had significantly higher quality of life scores during active treatment, which was consistent with findings that women with cervical cancer experience prolonged troublesome morbidity with treatment (Bergmark et al., 1999; Herzog & Wright, 2007; Jensen et al., 2003). At completion of treatment, the women with breast cancer scored

significantly lower on emotional functioning compared to women with gynecologic cancer. Interestingly, at six months and one year post treatment time intervals there were no significant differences between the women on any of the quality of life domains that were assessed.

Because of such mixed results it seems prudent to explore whether there is a difference for women after cervical cancer treatment related to 'time since treatment began' and if a difference is found, understanding the nature of the difference could be important. Exploring this variable could extend knowledge and it might become a prognostic factor that could be valuable when assisting women who experience cervical cancer treatment.

In summary, the literature review thus far, suggested that age was not an independent prognostic factor for survival in cervical cancer, though age clearly impacted cervical cancer outcomes for some women (Brun et al., 2003; Kastritis et al. 2007; Sawaya et al., 2001). Though there has been great progress in decreasing the incidence of cervical cancer, the data further suggested that there were still too many women dying from the disease (Merrill, Merrill & Mayer, 2000; Singh, Miller, Hankey & Edwards, 2004). And there were also too many women who must endure prolonged cervical cancer morbidity despite the technology available for early diagnosis and noninvasive treatment options (Carpenter, Andersen, Fowler & Maxwell, 2009; Jensen et al., 2003; Levin et al., 2010; Mouga, 2000). Pap test screening declined with age and cervical cancer incidence, morbidity and mortality increased with age (Brun et al., 2003; Merrill, Merrill & Mayer, 2000; Peterson et al., 2008; Wright et al., 2005).

There was evidence of racial/ethnic morbidity and mortality disparities that appeared to be unceasing and lead to painful questions (Corbie-Smith, Flagg, Doyle & O'Brien, 2002; Bradley, Given & Roberts, 2004; Farley et al., 2001; Newman & Garner, 2005). Explanations at times seemed to focus on cultural and behavioral traits (e.g. smoking, residence status, literacy, embarrassment, obesity, mood altering substance use) to explain the persistent inequality (Ferrante et al., 2000; Datta et al., 2006; Lantz et al., 2001; Schultz, Stava, Beck & Sellin, 2004) in combination with other important contributing aspects. Women with less education, less income, poor health status, including comorbidities, incarcerated, no health insurance or usual source of care or medical home were less likely to receive preventive health care or equitable care, particularly cervical cancer screening (Binswanger, Mueller, Clark & Cropsey, 2011; Farley et al., 2001; Peterson, Murff, Cui, Hargreaves & Fowke, 2008). Whether there were differences in receipt of cancer treatments or health care needs or preferences or racial bias or other intervening factors were not frequently stated directly. A confluence of all the problems often resulted in diagnoses of late disease stages or no staging for some women (Merrill, Merrill, & Mayer, 2000). The effect of SES was as powerful as age, race/ethnicity, cancer stage and the related disparities. The interactions among demographic and medical characteristics of women, particularly disadvantaged women, who experienced accumulations of stressors, remained unclear. The evidence advanced that the amount of 'time since treatment began' is not only important to women's adaptation after cervical cancer treatment, but also to the family of the women. Exploration of coping resources and women's sexual self-concept could inform how best to help women cope, adjust and effectively buffer the stressors associated with

cervical cancer and its treatment (focal stimuli) and the demographic characteristics, disease stage, health status and cancer stage and time since treatment began (contextual stimuli).

Coping-Adaptation Processes

Coping-adaptation is a strategy by which people seek control or mastery over stress with the implication that control or mastery over the stress if achieved, is productive or adaptive coping. Coping is defined in this study as the behavior and thoughts that women who have cervical cancer use to manage the disease and treatment in an effort not to be harmed and to adapt to the stressors (Folkman & Moskowitz, 2004). The definition presumes the presence of a stressor and a constructive response aimed at mitigating the threat (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1985; Taylor & Stanton, 2007). For women who have experienced cervical cancer and who are the focus of this research, the cancer treatment is the stressor. However, the experience of the disease itself is also stressful; particularly when at an advanced stage the treatment morbidity may be quite taxing and long-term (Bergmark et al. 2002; Jensen et al., 2003; Maher & Denton, 2008; Purnell & Andersen, 2009).

Coping strategies are integral to managing the morbidity and stress that accompanies cervical cancer treatment (Lutgendorf et al. 2000). According to most coping literature, coping is a dynamic process and is best understood in relation to the stimuli that initiates the need for the coping (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1985; Pargament, Feuille & Burdzy, 2011; Roy, 2009; Williams, Jerome, White & Fisher, 2006). Not only do stress related stimuli dictate whether coping is

initiated, it can also prescribe the intensity of the coping response. The intensity of the coping is not to be confused with efficacy of the coping process; coping strategies are not innately good or bad if they do not promote or yield healthy outcomes (Folkman & Moskowitz, 2004). To believe otherwise ignores the complexities that are involved in the coping processes. Complexities such as individual variability must be considered, since most people do not exercise precise differentiation between the various coping strategies employed (Cook & Heppner, 1997). Research findings are mixed regarding certain coping strategies yielding effective, good or healthy outcomes versus ineffective or unhealthy outcomes (Folkman & Moskowitz, 2004; Gray & Cason, 2002; Lutgendorf et al., 2000; Lazarus & Folkman, 1985; Pargament, FDeuille & Burdzy, 2011; Park & Adler, 2003; Penley, Tomaka & Wiebe, 2002). The current review evaluated the literature on cognitive and religious coping. Cognitive coping research will be discussed first.

Cognitive Coping

Cognitive coping has been studied extensively, but there were no studies regarding the effect of cognitive coping on women's sexual self-concept after cervical cancer treatment. While the idea of cognitive coping was acknowledged earlier by Andersen (1993), whether it would help to prevent or diminish a non-adaptive sexual self-concept after women experienced cervical cancer and treatment remained primarily theoretical. In general, stress coping theory, including cognitive coping theory, posits that the experience of stress depends on two cognitive appraisal processes: the individual's judgment of what is at stake and their available coping resources to deal with what is at stake (Lazarus & Folkman, 1985). To help explain how cognitive coping

may aid women to deal with what is at stake, Taylor's (1983) Theory of Cognitive Adaptation was applied as a theoretical referent and model. Aspects of Taylor's theory helped since there was only sparse information available at the time related to Roy's conceptualization of cognitive coping (Roy, 2009) and its relevance to women's sexual self-concept. Cognitive dissonance and regaining cognitive balance after experiencing cervical cancer treatment and difficult decision making seemed intricately related to the form that cognitive coping processes take (Andersen, 1993; Taylor & Stanton, 2007). Taylor (1983) and others (e.g. Taylor & Stanton, 2007; Thoits, 2010) posited that coping resources, such as optimism and control/mastery greatly assisted in the cognitive coping processes and could be capable enough to assist women's abilities to adjust after cancer. Coping resources (Stiegelis et al., 2003; Taylor & Stanton, 2007; Thoits, 1995; 2010) are defined as social and/or personal characteristics, which people have or learn to use when dealing with stressors and are associated with coping and cancer outcomes (Katz, Rodin & Devins, 1995; Purnell & Andersen, 2009). Optimism, defined simply as believing that something good will happen (Taylor & Stanton, 2007) and control/mastery defined as being able to influence outcomes (Taylor & Stanton, 2007) were of interest related to the current study. No studies were found regarding coping, coping resources and women with cervical cancer, therefore studies with diverse cancer participants were reviewed.

Even though coping resources have not been studied with women who had cervical cancer and treatment, there was an abundance of empirical support that connected optimism and control as promising resources related to cognitive coping for people with a variety of cancers and other life threatening illnesses such as AIDS

(Carver et al., 1994; Gray & Cason, 2002; Henselmans et al., 2010; Stiegelis et al., 2003; Taylor & Stanton, 2007; Thoits, 1995). For example, a frequently reported qualitative study conducted by Carver et al., (1994) involved 70 women who had early stage breast cancer. The study was longitudinal and primarily dealt with the effects of optimism versus pessimism on women's adjustment at diagnosis, and 3 months, 6 months and 12 months following diagnosis and treatment. Results indicated that women identified as optimistic were more accepting of the reality of the situation they were facing; they were less likely to put it aside and refuse to deal with it, they more actively pursued related goals. Optimism was viewed as a marker for assisting cognitive coping and adaptation following diagnosis and during the subsequent year. It was not entirely known whether optimism could be adaptive for everyone, particularly women with advanced cervical cancer, which justified further research exploration.

Research regarding whether control/mastery over stress add to positive adaptation has been equally important in studies of individuals with cancer. A longitudinal study included 92 breast cancer patients with a mean age of 57 years and over 50% were employed in an intermediate to high level professional position. The study was conducted by Henselmans et al., (2010) to confirm the adaptive effect of control/mastery. It was anticipated that women who reported control/mastery over their lives before a breast cancer diagnosis experienced less psychological distress after the diagnosis. The second expectation was that control/mastery reported after the diagnosis was related to less psychological distress up to two months after the end of treatment. Questionnaires were completed at four time intervals starting prior to diagnosis and up to seven months after diagnosis. The results included full support for

the first hypothesis by indicating that a strong sense of control over life before diagnosis protected women from distress immediately after the breast cancer diagnosis. The second hypothesis showed no changes in distress. The researchers offered as a possible explanation for the different findings related to distress that the study design may have been at fault; the predictor and outcomes may have been assessed at more meaningful times, such as during the illness related to the first hypothesis rather than after diagnosis related to the second hypothesis. Nevertheless, women with a low sense of control appraised cancer and their coping skills more negatively, which probably made them more vulnerable to distress. An interesting study conducted with 80 women with HIV/AIDS, of whom 50% were women of color, revealed similar successful mastery over stress in a cross-sectional study. The women had a mean age of 35.8 years and had attended some college, were unemployed and had a $15,000 annual household income. Mastery over stress was reported by 36% of the women (Gray & Cason, 2002).

Another longitudinal study of interest related to coping resources and cancer was conducted byStiegelis et al., (2003). The study proposed that adjustment after cancer depended on the ability of individuals to sustain and modify illusions of optimism and control, which was congruent with Taylor's Theory of Cognitive Adaptation (1983). Newly diagnosed participants with diverse types of cancers while coping with radiation therapy participated in the study. The perceptions of optimism and control/mastery of the participants who had cancer were compared to 50 healthy individuals as a control. Questionnaires were completed prior to the start of radiation therapy, two weeks after the start and three months after completion of treatment. Results revealed that cancer

patients reported greater optimism compared to the healthy referents. The results further suggested that productive/adaptive cognitions related to optimism and control/mastery were possible in patients with diverse cancer sites. However, no group differences between the cancer patients and the healthy references were found involving control/mastery. Interestingly, lower levels of optimism and control/mastery at time interval one was predictive of feelings of anxiety at time interval three, which was counter to findings in the Henselmans et al., (2010) study. Younger age and having a partner in the Stiegelis et al., (2003) study was significantly associated with higher levels of control. Lower perceived control/mastery also predicted feelings of depression.

Even though benefits of control/mastery and optimism have been extolled in the literature for people with cancer, there have been some contradictory findings and findings that stimulated questions and uncertainty about the impact of these coping resources (Adler & Snibbe, 2003; Lachman & Weaver, 1998; Taylor & Stanton, 2007; Thoits, 1995). These researchers acknowledged research findings that revealed a sense that control/mastery and optimism reduced psychological disturbances and buffered the effects of stress; they also questioned assumptions based on positive findings and generated new questions or uncertainty about the findings. For example, Thoits (1995) pointed out how researchers have presumed sometimes incorrectly, that individuals who displayed use of high levels of coping resources (e.g. control/mastery and/or optimism) also generally used effective or adaptive coping strategies (e. g. problem-focused strategies versus emotion-focused). Similar to Roy (2009), Adler & Snibbe, (2003) indicated that demographic and contextual stimuli, especially SES, are

believed to have a part in shaping individuals' cognitive tendencies. The thinking was that lower SES rendered fewer opportunities for control/mastery and optimism. However, it was noted prior to the current study that empirical support for this thinking is limited, since exploration of individuals' demographics, medical and biological characteristics and psychological adjustment/outcomes have rarely been revealed within one sample.

Additional findings by Lachman & Weaver (1998) indicated that individuals of low SES with high levels of perceived control/mastery sometimes had health outcomes comparable to individuals with high SES. Conversely, the authors discussed how in some circumstances high levels of control/mastery result in poor health outcomes, e.g. individuals associated with type-A personality behaviors have an increased risk for heart disease and other stress related illnesses. After conducting a retrospective study that examined whether social class differences related to control/mastery was adaptive for people at all levels of SES using three national data sets, Lachman & Weaver (1998) reported interesting findings. Between the groups, those with lower incomes appeared to have lower levels of perceived control/mastery, however with-in group differences suggested that some individuals with higher income levels also had a low sense of control/mastery and some at lower income levels had high levels of control/mastery. What makes the difference is not clearly understood and yields questions worthy of further investigation.

Relative to age, mixed findings regarding differences with cognitive coping was found in studies. In some cancer studies younger-aged women were found not to cope well. For example, in a study conducted by Wenzel et al., (1999) that examined quality

of life issues with women who had cancer, age-related findings emerged with younger women. Results suggested that younger women (under 50 years) had more problems adjusting to cancer than older women and it was thought to likely be due to younger women's lesser experience with cognitive coping strategies. Consistent with these findings it has been noted elsewhere that younger women are less skilled in coping with cancer treatment-related effects (Bergmark, Avall-Lundqvist, Dickman, Henningsohn & Steineck, 2002; Carpenter, Andersen, Fowler & Maxwell, 2009; Wenzel et al., 2005).

Similar findings were noted in an age-comparative longitudinal study conducted by Diehl, Coyle & Labouvie-Vief (1996) concerning the use of conscious and unconscious coping. Participants had a mean age of 44 years with the range up to 70 years. Most were White, married, with a middle class income and well educated. As the participants aged they were noted to use more refined cognitive coping strategies. Further findings suggested that developmental progress in coping strategy utilization was influenced not only by age, but also by life experiences and cognitive development, particularly verbal ability. The participants became increasingly more effective and flexible in coping as they aged and after more life experiences. Generalizabity of the findings was limited to non-diverse, educated individuals, well above the poverty line.

In contrast to findings from the Wenzel et al., (1999) and Diehl (1996) studies, a study of 100 women with breast cancer found that younger women rather than older women used more adaptive coping strategies (Schnoll, Harlow, Stolbach & Brandt, 1998). Relationships among age, disease stage, coping style and psychological adjustment were examined in the study. The mean age was 44 years. A majority of the women were married and had a college education. Income and race/ethnicity was not

reported. A consistent pattern emerged throughout the analyses, which revealed that younger women reported use of more adaptive coping styles (e.g. a fighting spirit) and less non-adaptive coping styles (e.g. hopelessness, fatalism) compared to older women with more advanced disease stages. Still, the study informed the utility of cognitive coping as a mediator between focal (and contextual) stimuli and sexual self-concept. Women with cervical cancer could learn to buffer the impact of cervical cancer and treatment with coping resources and strategies. Since little is known about the complex nature of the relationships among, age, coping and sexual self-concept.

Overall, the literature appeared to be mixed concerning whether coping resources and cognitive coping was adaptive and to whom it was adaptive for. While there were exceptions, many researchers have found that Black individuals are exposed to greater stress than other racial groups (Carpenter, Andersen, Fowler & Maxwell, 2009; Eggleston et al., 2006; Farley et al., 2001; Meyer, Schwartz & Frost, 2008), though evidence displaying cognitive coping among diverse people was almost nonexistent. Support in the literature regarding cognitive coping, age and gender was also mixed and sparse. Higher education appeared to contribute to coping and adaptation (Diehl, Coyle & Labouvie-Vief, 1996; Schnoll, Harlow, Stolbach & Brandt, 1998). Whether the development or maintenance of coping resources, such as optimism and control/mastery could aid women who had cervical cancer and treatment is unknown. Further research is needed to identify whether women with cervical cancer, might be able to maintain or develop productive or adaptive beliefs in the face of continuous cervical cancer morbidity and the risk of mortality. Whether class differences (e.g. SES) impede benefits related of coping resources among women who

had cervical cancer and treatment was important to explore (Lachman & Weaver, 1998). Since poor uneducated women have the worse outcomes related to cervical cancer and treatment, further exploration was justified. Interventions that buffer the effects of lower SES with poor women, e.g. assisting women to develop better coping skills, particularly relative to perceived control of the situation (Henselmans et al., (2010) and restoring or adding to the women's hope and optimism (Taylor & Stanton, 2007) might help prevent or diminish further morbidity and mortality.

Religious Coping

Little has been documented and subsequently, little was known about the impact of religious coping with sexual self-concept and cancer. The paucity of research related to this topic illustrated the need for additional empirical work and established an opportunity for significant knowledge contributions from the current study. A couple of studies explored a subtle linkage between religious coping and different illnesses (Holmes, 2002; Wagner & Rehfuss, 2008), but no research was found that assessed these concepts in a population of women who have undergone cervical cancer treatment. The Holmes (2000) study investigated whether sexual self-concept discrepancies (based on self-concept discrepancy theory related to multiple self-concepts in conflict with one another), and decreased religiosity would result in mental health problems (e.g. depression, anxiety, agitation or feelings of dejection). Religiosity was assessed by asking: how religious are you? How often do you attend religious services? How often do you pray? The sample included young (mean age 20 years) female Black college students, primarily from middle-class families and the majority of the participants reported practicing Christianity. Results revealed little sexual self-

concept discrepancies, no mental health problems and religiosity was not associated with better mental health for the sample. The findings suggested that sexual self-concept discrepancies may be different for Black women and/or measurement of discrepancies may require a different process. The authors also stated that religion was protective for Black women.

Religion was found to be less protective in the Wagner & Rehfuss (2008) qualitative study when sexual self-concept and religion was explored related to self-injury behavior among three young (mean age 22 years) White female college students. The young women reported their religion to be Christian and attended a small private Christian university. Further findings revealed the women had similar perceptions regarding their religious upbringing that included a "negative or limited view of sexuality" (p. 176) creating ambivalence with sexual self-concept. The self-injury behavior was how the young women coped with relational stress particularly with the opposite sex.

In general, religious beliefs have had a mixed impact on women's sexual self concept; positive and negative (Farmer, Trapnell & Meston, 2009) depending on women's own perceptions and perceptions of others, particularly of religion as a coping resource (Pargament, 2002). No studies were found that dealt with cervical cancer and religious coping. Moreover, nothing was found from a religious context that empowered women to feel comfortable discussing or expressing sexual beliefs, feelings, and attitudes about sexual behavior or sexual health. Nor was information found about whether religion was a hindrance, help or both related to sexual self-concept or how these feelings might impact positive or negative religious coping.

Since cervical cancer is a sexually transmitted cancer and women suffer the stigma associated with the condition (Sevin, 1999), it is reasonable to expect that some women may engage in negative religious coping and endure adverse effects to one's sexual self–concept. How cervical cancer and treatments may actually influence coping and quality of life outcomes for women are not known. Social implications seem to support the stigma and blame associated with cervical cancer. The stigma persists due to the above etiologic link and sexual double standards that women have historically been exposed to in the United States (e.g. contradictory sexual messages, more disapproval of a sexually active female than a sexually active male) (Katz & Farrow, 2000). A contentious relationship between religion and sexuality have at times provided direct and indirect social influence that contributed to negative religious coping by women, adversely effecting their sexual self-concept (Davidson, Darling & Norton, 1995; Sevin, 1999).

While it has been reasonable to believe that social experiences can cause religious dissonance in women, the greater concern or "red flag" related to negative religious coping is the association with poorer health outcomes and greater psychological distress (Pargament, 2002; Pargament et al. 1998). However in contrast, it is important to note that religious struggle has also been known to be associated with spiritual growth and maturity for some individuals. Such positive benefits were typically reported following experiences of struggles (e.g. a life threatening illness like cancer) and less so while individuals were in the throes of such events, the time during which poorer health outcomes generally occurred (Pargament, 2002; Williams, Jerome, White & Fisher, 2006). Alternatively, there have been research findings that suggested the

discovery of something good in the bad have not always been found to be good later (e.g. months later), particularly if denial proliferated and benefit finding became non-adaptive or maladaptive (Tomich & Helgeson, 2004).

Moreover, most empirical research measured religion as a demographic characteristic and used organized religious frameworks (e.g. Jewish, Catholic). Few studies (Pargament & Park, 1995) conceptualized religious coping from the complex perspective that it can be. According to Pargament (1997) the religious coping process is a well integrated process and is activated by the demands of the stressor and the emergence of a-priori conditioned pattern of behavior(s), also known as an a-priori orienting system or a general orienting system (Hill & Gibson, 2008; Harrison, Koenig, Hays, Eme – Akwari & Pargament, 2001; Pargament et al., 1992). For many people the conditioned pattern of behavior or orienting system involves religion when religion is available (e.g. from past socialization, conditioning). During stressful times the orienting system emerges and is translated into coping strategies and behavior(s) that can be adaptive or non-adaptive (Hill & Gibson, 2008; Pargament, 1997; Pargament et al., 1992). For those who identify as being spiritual rather than religious or do not identify as either, a reliance on what is referred to as inner strength may be considered as the usual orienting system that emerges.

Pargament and colleagues (1990) provided empirical examples of how people commonly relied on a general religious orienting system to cope with stressful events. O'Brien (1982) interviewed 126 chronic dialysis patients and the majority (n=74%) reported that religious beliefs related to their ability to cope with the disease and treatment; McRae (1984) asked a sample of 255 men and women to check coping

mechanisms they used to deal with a previously reported stressful event and faith was reported by 75% of the sample dealing with a loss or facing a soon to occur threatening event; Koenig, George & Siegler (1988) asked a random sample of 100 older adults to describe the coping behaviors they used to deal with three stressful events and 45% of the sample cited religious coping behaviors more frequently compared to other behaviors. The Pargament team (1990) conducted further research with 586 participants to explore the extent of the helpfulness that religious coping efforts provided to those who turned to religion when dealing with negative events. Results indicated that religious coping activities commonly contributed to the coping process for those who relied on it. In a follow-up study (Pargament et al., 1992), religion was viewed as bridging or mediating the relationship between negative life events and outcomes. While this research was generated over two decades ago, the findings still have utility (Hill & Gibson, 2008), though interest currently includes not just whether people used religion, but also how people used religious resources to cope. However, there are no easy or simple answers and no standard mechanisms to get to the answers and more questions have resulted. Therefore, the current study was timely.

Other studies have contributed useful knowledge. For example, a study conducted by Bourjolly (1998) examined differences between White and Black breast cancer patients in the use of religion as a coping resource. A convenience sample of 102 women (n=61 White and n=41 Black) treated for their breast cancer with a lumpectomy (not mastectomy) and radiation therapy were eligible to be in the study. There were significant demographic and "religiousness" differences among the two groups of women. White women compared to Black women on average were younger,

better educated, 72% were married with a mean income of $57,000, more than double the mean income of the Black women in the study whose income mean was $28,000.The majority of the White women lived in the suburbs with no children less than five years old compared to the majority of Black women, who lived in the city and 10% of the Black women had children under five years old. There were also significant differences related to the measure of "religiousness" between the women. The Black women scored higher on public and private "religiousness" (public participation was with organized religious groups, private participation was internal, solitary use of religion): (White women, *M*=2.7; Black women, *M*=3.4, *p*=.000), (White women, *M*=2.8; Black women, *M*=3.7, *p*=.000). The total "religiousness" score was therefore significantly different between the two groups with Black women scoring higher. The stepwise regression with public and private "religiousness" revealed that race was a significant contributor to the differences in "religiousness". Overall, Black women relied on religion as a form of coping more than White women. While not generalizable beyond the sample, the knowledge gained from the study might help to inform assessment and intervention potential with White and non-White women after cervical cancer treatment.

Another study (Pena & Frehill, 1998) involved the complexity and nuances of religious beliefs of 12 focus groups of Latina women in eight U.S. cities which revealed the complexity that surrounded religious coping. The purpose of the study was to explore issues related to culture, religiosity and how information about these might be used to broaden understanding of religiosity. Participants were American women with ethnic origins from several Latin countries. Participants' mean age was 40 years, 32% reported high school diploma or less, 33% reported some college and 34% reported

bachelor degrees or above. The results disclosed how women challenged imposed patriarchal religious expectations by taking control of decisions about their bodies and life situations. The findings uniquely revealed the women's public expression of strength and courage, possibly due to the focus group process. Some of the women reported using forbidden methods of birth control, some secretly underwent sterilization procedures and others reported coaxing husbands to undergo vasectomies. One woman reported how she rejected the church's expected partnership role of women in marriage and instead formed her own sense of "empowered spirituality" (p 627) following an abusive marital relationship and unhelpful counseling from her priest. The experience and self-learning brought adaptation, healing, empowerment and newly discovered love for herself and her body, similar to women after cervical cancer and treatment and an adaptive sexual self-concept. The results also identified two distinct ways that religion was practiced by the women; social (more public) and personal (more private) forms of practices. The personal practices were the ones more aligned with popular (as opposed to traditional) views of religion and broke away from the "patriarchal-defined" Mary, who was submissive, naïve, childlike and pure. Instead, women interestingly identified a "God-like" Mary. Religiosity measures indicated women of Cuban descent were most religious and Puerto Rican women were least religious with Mexican women exhibiting scores between those of the Cuban and Puerto Rican women. The recognition that women in general and specifically are many times marginalized in religion, yet some are actively engaged and aware of how to cope with the religious restraints and shape their own religious reality can be instructive.

A third study (Banthia, Moskowitz, Acree & Folkman, 2007) uncovered associated relations of socio-demographic variables (race/ethnicity, age, education, income), health symptomatology and religious practices (prayers, religiosity) of maternal caregivers of children with HIV/AIDS and other chronic illnesses. The mean age of the caregivers was 42 years and the mean age of the children was eight years. Overall, findings revealed that education had more influence than ethnicity or income on religious practices and reported health symptoms. An inverse relationship was identified between religious practices, education and income. White caregivers had the highest income and number of years of education compared to Latina women who had the lowest levels of both variables. African American caregivers had the highest levels of religious practices compared to White caregivers, who had the lowest. Both, education and ethnicity moderated relations between prayer and reported health symptoms and the least educated had the highest levels of religious practices and fewer health symptoms.

Demographics such as women of color including African American, White and Black Hispanic women, higher age, lower education and income appeared to covary (Tomich & Helgeson, 2004) with increased religious practices/prayer (Banthia, Moskiwitz, Acree & Folkman, 2007; Boutjolly, 1998; Pena & Frehill, 1998). Such knowledge could help direct assistance with women's positive or negative religious coping. Women used religion as a coping mechanism more than men (Williams, Jerome, White, & Fisher, 2006) and were known to more readily seek help to deal with their cancer and treatment (Holt et al. 2009; Purnell & Andersen, 2009). However, whether religious coping can be helpful or harmful, adaptive or non-adaptive during and

following cervical cancer treatment was not known. Such determinations are related to the "goodness of fit" of the coping strategy to the specific stressor (Hill & Gibson, 2008, p. 27), including one's general orienting system, characteristics (demographics and coping resources e.g. the sense of optimism and control/mastery) of the individuals dealing with the coping situations and the context (e.g. after cervical cancer treatment) during which coping occurs (Pargament, 2002; Pargament, Feuille & Burdzy, 2011). Examination of associations among these variables was further justified based on the results of the above studies and related questions and interest in assisting women after cervical cancer and treatment.

Sexual Self-Concept (Output)

Sexual self-concept, an important part of self-concept, is defined as a combination of perceptions, beliefs, attitudes and feelings that women hold about their sexual selves (Markus, 1987; Roy & Andrews, 1999; Roy, 2009; Vickberg & Deaux, 2005). Just as self-concept is believed to be integral to a person's whole being (Markus, 1987; Roy, 2009), sexual self-concept is conjectured to also be an important part of women's holism (completeness). Similar to self-concept, women's cognitions (also known as cognitive generalizations or representations) about their sexual self and sexual knowledge was believed to be derived in part, from their perceptions and the perceptions of others (Andersen, 1999; Katz & Farrow, 2000; Roy, 2009). The consequences of certainty and importance of these perceptions with sexual cognitions and self-views are indicated by women's cognitive information processing, sexual self-concept and behavior (Andersen, 1999; Andersen and Cyranowski, 1994; Carpenter, Andersen, Fowler & Maxwell, 2009; Garcia, 1999; Pelham, 1991; Roy, 2009). However,

not much is known empirically about women's sexual cognitions, sexual self-perceptions (Zeanah & Schwarz, 1996) or sexual self-concept (Vickberg & Deaux, 2005), which was the focus of the current study There has been an abundance of research conducted on sexuality and sexual behavior, but not as much on sexual self-concept.

It was well known that self-concept is multidimensional (Markus, 1977; Pelham 1991; Roy, 2009) and it is believed to be the same for sexual self-concept (Cleary & Hegarty, 2011; Vickberg & Deaux, 2005). However, only two dimensions of sexual self-concept, sexual-esteem and sexual satisfaction (Andersen, 1999; Cleary & Hegarty, 2011; Snell, 2001) were integral to the current study and was used to operationalize sexual self-concept (Snell, 2001). Empirical evidence have repeatedly revealed an association of sexual-esteem and sexual satisfaction to sexual self-concept (Andersen, 1999; Andersen & Cyranowski, 1994; Carpenter, Andersen, Fowler & Maxwell, 2009; Cleary & Hegarty, 2011; McCabe & Taleporos, 2003; Rehbein-Narvaez, Garcia-Vazquez & Madson, 2006). For example, Andersen (1999) and Andersen & Cyranowski (1994) emphasized how women with high levels of sexual-esteem have positive sexual self-concepts, considered themselves as being more sexual as well as secure enough to foster intimate and friendly relationships with others. Carpenter and her colleagues (2009) examined sexual satisfaction in relation to sexual self-concept along with other quality of life issues. Findings not only suggested an association between sexual self-concept and sexual satisfaction, but also that problems with one could buffer or protect women from added problems with the other. If sexual satisfaction is low, yet women's sexual self-concept remained positive, the positive

sexual self-concept could act as a moderator and buffer or protect women from further negative distress. A comprehensive literature review was performed by Cleary & Hegarty (2011) that helped bring clarity to the words 'sexuality' and 'self-concept' in the context of gynecologic cancer. Several related dimensions of sexual self-concept were discussed, most importantly sexual-esteem, indicating the relationship to sexual self-concept. Rehbein-Narvaez's team (2006) research findings were similar to the point made by Andersen, that women with higher sexual-esteem reported greater sexual satisfaction resulting in higher sexual functioning. An association of sexual-esteem and sexual satisfaction to sexual self-concept was also seen in the study by McCabe & Taleporos, (2003). The study was conducted to investigate associations among variables, including sexual-esteem and sexual satisfaction with the severity and duration of physical disability. The findings indicated that problems in sexual response (equivalent to sexual self-concept) due to disabilities were seen via sexual-esteem, sexual satisfaction and sexual behavior with individuals. Individuals with lower sexual self concept and esteem ultimately engaged in fewer sexual activities, which concurred with findings by Andersen & Cyranowski (1994) of a negative sexual self-concept.

Further conceptualization of sexual-esteem in this study was based on how self-esteem was treated by Roy (2009) and several other researchers (Bartoces et al. 2009; Katz, Rodin & Devins, 1995; Taylor & Stanton, 2007; Thoits, 2010). Self-esteem appeared to be embraced by Roy and others as an antecedent to adaptation after illness, particularly cancer. Thus, sexual-esteem was patterned after self-esteem as well as being considered a significant and necessary part of women's sexual self-concept. If lowered after cervical cancer and treatment, women's coping and sexual

self-concept would be handicapped (Andersen, 1999; Gamel, Hengeveld & Davis, 2000).

Among the few studies related to sexual self-concept, only one study has been conducted solely with Black women (Holmes, 2002). Prior to this study most participants included in sexual self-concept research were White non-Hispanic young college students or adolescents. The study dealt with mental health consequences of sexual self-concept discrepancies, namely what women felt and desired about their sexual selves and whether it related to mental health problems. The women had minimal discrepancies with no mental health problems, which was unexpected and led the researcher to conclude that such discrepancies were not central to predicting mental health in Black women. It was also concluded that the women's unexpected reactions possibly emerged in opposition to the usual negative sexual stereotypes about Black women. Overall, the findings seemed to suggest that sexual self-concept discrepancies may be different for Black women and/or measurement of discrepancies may require a different process.

Interestingly, five studies exploring sexual self-concept were (Breakwell & Millward, 1997; Impett & Tolman, 2006; O'Sullivan, Bahlburg & McKeague, 2006; Rostosky, Dekhtyar, Cupp & Anderman, 2008; Winter, 1988) conducted with adolescents, primarily related to sexual risk-taking and sexual health promotion. While the studies were unrelated to an adaptive sexual self-concept, one of two studies worth noting was conducted by Rostosky, Dekhtyar, Cupp & Anderman (2008). The study examined associations among sexual self-concept (which included two components: sexual-esteem and sexual anxiety) and sexual self-efficacy or mastery (which included

two components: resistive self-efficacy and sexual situational self-efficacy). The sample included Black and White adolescents with a mean age of 15 years. Results showed that female adolescents reported higher sexual-esteem and sexual efficacy and lower sexual anxiety. Sexual-esteem mediated relations between knowledge of sexual risk and both types of sexual self-efficacy or mastery. The overall findings suggested that adolescent sexual-esteem helped translate knowledge of sexual risk that preserved safety of sexual health and sexual self-concept. The finding further suggested that sexual-esteem was not only protective, but also related to sexual self-concept. This lent additional empirical support for sexual-esteem as an important component of sexual self-concept. The second study with adolescent females (Impett & Tolman,2006), found that sexual self-concept, similar to findings with adult women (Andersen & Cyranowski, 1994), was associated with more sexual experience and sexual satisfaction (a component significant to the current study). However, it was not related to greater numbers of partners or earlier coital experience.

Important seminal studies included research conducted approximately two decades ago by Andersen and colleagues that focused primarily on sexual morbidity for female cancer survivors of mostly breast and gynecologic cancer (Andersen and Cyranowski, 1994; Cyranowski & Andersen, 2000; Andersen & Elliot, 1993; Andersen & Hacker, 1983; Andersen & Jochimsen, 1985; Andersen, Woods & Copeland, 1997). Among the major contributions of this work was the development of a risk model reported to predict sexual difficulties following gynecologic cancer and treatment (Andersen, 1993). Specifically, the model provided a framework for determining the predictive utility of sexual self-concept in forecasting sexual difficulties following cancer

and treatments (Andersen, Woods & Copeland, 1997). The variables emphasized in the earliest risk model were referred to as predisposing factors alluding to problems identified by women at the time the disease was detected (e.g. fatigue, postcoital bleeding, vaginal discharge, and/or pain) and other variables such as socio-demographics (e.g. age, race, education and income), prior health status (physical and mental), social network/support, and other stressors. The stage of disease and treatment recommendation was included as next steps in the risk model. Consideration of risk-reduction interventions was also included with assessment for new problems, stressors or treatment (Andersen, 1999).

Rationale was offered for including each variable in the risk model (Andersen, 1993) and 19 years later the rationale was still valid and useful for the current study. For example, sociodemographic variables were believed to be mediators for health promotion and/or health decrements (e.g. risk of cancer) and poor survival was known to increase with age (Andersen, 1993; Coker, Du, Fang & Eggleston, 2006; Wright et al., 2005). The well known increased distress among younger-aged women (Andersen, 1993; Bergmark, Avall-Lundqvist, Dickman, Henningsohn & Steineck, 1999; Carpenter, Andersen, Fowler & Maxwell, 2009) and poor survival among women of nonwhite race (Andersen, 1993; Eggleston et al., 2006; Merrill, Merrill & Mayer, 2000) and low SES co-varied with diminished access to health care, poor health status, poor treatment and morbidity outcomes, and poor survival (Andersen, 1993; Brooks et al., 2000b; Eggleston et al., 2006; Woods, Rachet & Coleman, 2006). Prior health status, particularly related to comorbidities have been shown to negatively affect health outcomes (Andersen, 1993; Brooks et al., 2000b; Carpenter, Andersen, Fowler &

Maxwell, 2009). and social support was frequently found to positively augment health outcomes for people with cancer and was an important asset for cancer patients (Andersen, 1993; Donovan et al., 2007). Other stressors and the magnitude of the disease and treatment have been associated with health outcomes repeatedly (Brooks et al., 2000b; Merrill, Merrill & Mayer, 2000; Waggoner, 2003).

Not all of the variables have been empirically tested. Only one study (Andersen, Woods & Copeland, 1997) was found that appeared to test the risk-model. The study was conducted while testing a sexual self-concept tool (also known as Sexual Self-Schema Scale) previously developed in 1994 by Andersen & Cyranowski. Participants were primarily white gynecologic cancer survivors with cervical, ovarian, endometrial, vulva and vagina cancer, who reported a middle-class income. A control group of healthy women were included in the study with similar demographics except the control group was significantly (statistically) younger and better educated. Variables included in the study were demographic, health status, social network, stressors and extent of disease and treatment variables. New variables not previously in the model were added to measure sexuality and sexual functioning.

Results revealed additional group differences between the control group and the women with cancer in that the cancer survivors reported greater sexual morbidity. Further findings confirmed the applicability of the sexual self-concept tool. A second part was added to the study that tested correlates of risk for sexual morbidity. Two hierarchical regression analyses were performed. The first analysis revealed with each variable added sequentially (prior intercourse frequency, extent of treatment, menopausal symptoms, and sexual self-concept score) a total of 48% of the variance

was accounted for and the sexual self-concept scores were only 6% of that total. A second analysis was conducted to reportedly predict current sexual responsiveness "operationalized by the total sum of the scores for the phases of desire, excitement, orgasm, resolution and general" (Andersen, Woods & Copeland, 1997, p. 226). Reported results stated that sexual self-concept was the greatest predictor with a contribution of 28% of the variance and the entire model represented 34% of the variance. Prior levels of sexual activity, menopausal symptoms and surprisingly, extent of treatment contributed lesser amounts. This initial work on the risk-model to predict women at risk for sexual morbidity and albeit, a non-adaptive sexual self-concept due to cancer treatment contributed to the state of the science and practice of the cancer survivorship trajectory and it helped to inform the current study.

Overall, there have been no empirical studies that examined cervical cancer treatment, cognitive and religious coping and sexual self-concept within one sample. Various studies have been done individually with cognitive or religious coping without sexual self-concept and only a limited number of studies were conducted related to sexual self-concept without cognitive or religious coping. Of the limited studies of sexual self-concept only two were known to use theoretical frameworks (Andersen & Cyranowski, 1994; Andersen, Woods & Copeland, 1997). Many study samples were small and with little diversity (Andersen, Woods & Cyranowski, 1994; Vickberg & Deaux, 2005). Participants with a variety of gynecologic cancers, breast cancer, different stages and treatments were combined in many of the same studies. Additionally, some studies were conducted in Europe and Canada, which could possibly generate questions related to generalizability (Bergmark et al., 1999, 2002; Jensen et al. 2003,

2004). Interestingly, studies did not require participants to have partners, yet many times frequency of sexual intercourse as a form of partner intimacy was used as an outcome or indicator of sexual problems (Andersen & Cyranowski, 1994; Cyranowski & Andersen, 2000). In fact, sexual self-concept was usually translated to relate to physical sexual functions as opposed to applying a holistic psychosocial perspective, which is generally thought of as a feminine perspective (Cleary & Hegarty, 2011; Wilmoth, 2001). No research was found concerning sexual self-perceptions, which appeared to be influential for sexual self-concept and sexual behavior of women (Andersen, 1999; Andersen & Cyranowski, 1994; Zeanah & Schwarz, 1996). A mixture of demographic information was provided in many studies without consistency in the type and amount.

Chapter 3

Methods

This chapter addresses the methodological procedures that were implemented in the research study. The sections included in this chapter are research design, sample criteria and power analysis, recruitment and setting, measurement tools, data collection procedures, and lastly data management and preliminary analyses. The overall purpose of the study was to examine associations among cervical cancer treatment, select demographic variables, coping and sexual self-concept.

Design

A cross–sectional, descriptive correlational design was utilized to examine the relationships among cervical cancer treatment (e.g. surgery, radiation therapy, chemotherapy and combinations), select demographic variables (e.g. time since treatment began, cervical cancer stage, age, race, health status [perception and number of diseases], SES [education and income]), coping (e.g. cognitive coping and religious coping) and sexual self–concept (e.g. sexual-esteem and sexual satisfaction).

Sample and Power Analysis

Inclusion criteria for the sample was female, 18 years of age and older, able to read and understand English, only the first treatment for cervical cancer had occurred, and treated only in the U.S. The age limit of 18 years was prescribed for inclusion in the study because cervical cancer tends to affect younger women as well as women 60 and over (Greimel, Winter, Kapp & Haas, 2009; Sawaya et al. 2001). Young adult women 18 years and over are affected frequently with pre-cancer lesions (Michigan Cancer Goals for 2009-2015, 2011), but are not recommended to be screened for cervical problems until age 21. If the presence of lifestyle practices or cervical problems

dictates, screening may began sooner than at 21 years of age, but the current recommendations advise against cervical cancer screening prior to age 18. The cervical screening guidelines (ACS, 2011) recommend that women begin cervical cancer screening three years after the first sexual debut, but no later than 21 years of age. The inclusion requirement of women currently receiving treatment for at least three months (Gamel, Hengeveld & Davis, 2000; Andersen & Jochimsen, 1985) was generated based on a literature review that revealed mixed findings related to the time that physical and sexual morbidity problems generally emerge after treatment (Grumann, Robertson, Hacker & Sommer, 2001; Jensen et al. 2004). Exclusion criteria included women who had never been treated for cervical cancer or who were currently under the care of a provider for recurrent cervical cancer or had been treated outside the United States. Treatment for recurrent cervical cancer can vary according to individual needs and it may have been possible that treatment outside of the U.S. varied in some unknown manner compared to treatment in the United States. To prevent confounding the results these exclusions were maintained.

Power Analysis

A power analysis with the G*power computer software (Version 3) was used to calculate the required sample size (Faul, Erdfelder, Lang & Buchner, 2007). A sample size of 114 was required for the regression analyses based on a formulation of 80 percent power, an effect size of 0.15, at least nine predictors, and a 0.05 significance level. Based on the insufficient sample size to conduct the above analyses, predictors were reduced to seven (e.g. cervical cancer treatment, time since treatment began, cervical cancer stage, age, race, health status, SES [education and income]).

Recruitment and Setting

Approval for the study was obtained from Wayne State University's (WSU) Human Investigation Committee (HIC) before the study commenced. Three approved HIC amendments were obtained to extend recruitment strategies. Approval was granted to post flyers at St. John's Cancer Center, on Facebook, and in the following newspapers: Michigan Chronicle, Detroit Free Press, New Monitor, and Metro Times. Initial support was obtained to display flyers at the Henry Ford Health System's Gynecologic-Oncology Cancer, Oakwood Gynecologic-Oncology Cancer Center, Providence Cancer Center and Hurley-Genesys Cancer Institute in Flint, Michigan. Ultimately, approval was granted by two of the organizations: Henry Ford Health System and Hurley-Genesys Cancer Institute in Flint, Michigan, though time did not permit further pursuit of HIC agreements to use the organizations.

The study was conducted online via the internet and WSU HIC approval included permission to recruit for research participants through electronic invitation or advertisement from two online cancer organizations. Two of the online cancer organizations hosted advertisements and/or invitations on multiple websites owned by the organizations with links to the research questionnaire. In an effort to counter the slow response rate to the questionnaire the online host for the questionnaire provided assistance that offered remuneration to help reach the target audience. Additional responses were obtained from 28 women just prior to the end of the data collection.

The first online organization that hosted research advertisements and/or invitations to join the study included the National Cervical Cancer Coalition (NCCC). The NCCC was founded in 1996 and is a grassroots nonprofit organization dedicated to

serving women with or at risk for cervical cancer and HPV disease. The number of individuals who had previously or regularly visited the various web sites were not released to the principal investigator (PI) but the NCCC reported a membership of over 6500, of whom 5500 are located in the United States and Canada. The second online organization was the Michigan Cancer Consortium (MCC). The MCC is a statewide, broad based organization that strives to partner with all interested public and private organizations and provides a forum for collaboration to reduce the burden of cancer in Michigan. Cervical cancer is one of the special project workgroups within the MCC.

Instruments

A total of eight instruments were combined into one online survey tool with a combined total of 71 items. The eight tools included a demographic and health status form, four coping subscales taken from two larger coping instruments, two sexual self-concept subscales taken from a larger instrument measuring sexual self-concept and a measure of social desirability. In the current study all the scales were found to have good variability, moderate to high alpha scores and variable scale means. Complete psychometrics for all scales used in the study are reported in Table one.

The Demographic and Health Status (DHS) Form. The DHS form provided information regarding the focal and contextual stimuli (e.g. cancer stage, surgery, radiation therapy, chemotherapy and combinations, and time treatments began/ended, age, race/ethnicity, health history with comorbidities, perceived health status, current medications, income, education), relationship status, sexual orientation, religion history, sexual health history and confidant with whom sexual problems are discussed.

The Coping Adaptation Processing Scale (CAPS) (Roy, 2001, 2009, 2011).

The CAPS was developed by Roy (2011), creator of the RAM, as a rejoinder to the on-going challenge of how to measure the multidimensional construct of coping (Folkman & Moskowitz, 2004) and cognitive coping. The development of CAPS was specifically based on the conceptualization of the cognator and regulator coping processes, important components of the RAM and the SHA Theory, which was derived from RAM. Additionally, as an important variable for establishing research based nursing practice, CAPS measured how prudently people, whether sick or well, coped and adapted to their environments (Roy, 2011). Factor analysis revealed five subscales, which were interpreted within the middle-range theory of coping and adaptation processing. The five factors identified major dimensions to understand the coping construct: Resourceful and Focused Subscale, Systematic Processing Subscale, Physical and Fixed Subscale, Alert Processing Subscale and Knowing and Relating Subscale. The CAPS contain a total 47 items with a Likert scale format ranging from 1 (never) to 4 (always).

As a result of piloting the Cervical Cancer Questionnaire prior to implementing the current study, a suggestion was offered by a majority of the pilot participants to add a fifth category, “most of the time”. The suggestion was honored and the category was added to the original Likert scale format of the CAPS subscales. This was done with the permission of the author of the subscales (Dr. C. Roy, personal communication, March 5, 2012). Each item is a short statement of how an individual responded during a crisis or an extremely difficult event. The CAPS has been used in previous empirical studies among various populations, including adults in the community with stable neurologic deficits; elders adjusting to physical changes of hearing loss, same day surgical patients, and patients with ischemic cardiac disease (Roy, 2009). The score

ranges from 47 to 188 with a high score indicating a more consistent use of the identified strategies of coping. Reliability has been established with an alpha coefficient of 0.85. Concurrent validity was established with all of the subscales by significant correlations with subscales of the Ways of Coping instrument.

Two CAPS subscales thought to aid in identification of optimism and control/mastery as well as measure women's cognitive coping capacity were used in the current study. The subscales were chosen after being reviewed by volunteer experts to confirm the subscales' capacity to identify optimism and control/mastery. Three volunteer-professional experts: two doctoral prepared nurse-researchers and a board certified chaplain and manager of spiritual care services in a large urban tertiary level hospital were recruited to review the subscales. These experts were recruited because of their nursing and coping experiences with patients. A decision was made to use the Resourceful and Focused (will be referred to as Focused or Focus) subscale to help identify women's use of optimism and the Systematic Processing (will be referred to as Processing or Process) subscale to help identify women's use of control/mastery and to measure cognitive coping with the use of both subscales. Though the SHA Theory was not being tested with the current study, selection of an instrument (e.g. CAPS [developed by Roy, 2001]) that was congruent with the theory (the SHA Theory was derived based on RAM [Roy's Adaptation Model]) was pivotal to testing hypotheses that reflected the theory process (Boston Based Adaptation Research in Nursing Society, 1999).

The Resourceful and Focused Subscale (10 items) was a major dimension of the construct of coping and adaptation processing that reflected behaviors used by an

individual and focused on use of self and resources and concentrated on expanding input, being optimistic, inventive and seeking outcomes. The subscale score was obtained by summing the numeric responses for all items. Cronbach's alpha was 0.94 in the current. For the score range see Table one.

The Systematic Processing Subscale (6 items) described personal and physical strategies to take in situations and methodically take charge or control of the situation. Similarly, the subscale score was obtained by summing the numeric responses for all items. The subscale score was obtained by summing the numeric responses for all items. Cronbach's alpha was 0.86 in the current study and the score range can be viewed in Table one.

The Brief RCOPE (Pargament, Feuille & Burdzy, 2011). The Brief RCOPE, in which the "R" stands for religion, was based on the full RCOPE that consists of 21 subscales with a total of 102 items. The RCOPE was reported as performing well but it has not been widely used due to its length. With the discovery that many of the items in the full RCOPE could be clearly categorized as either positive or negative in nature, a subset of items were selected to create positive and negative coping patterns. Exploratory and confirmatory factor analysis was conducted with at least two or more groups; among the groups were hospitalized elderly patients and a second sample of college students, which indicated the two-factor solution fit the data adequately (Pargament, Feuille & Burdzy, 2011; Pargament, Smith, Koenig & Perez, 1998). The analysis eventually yielded the final Brief RCOPE, which was divided into two subscales (Positive Religious Coping and Negative Religious Coping); each consisting of seven items.

While the Brief RCOPE has been used throughout the United States (Cole, 2005; Pargament, Koenig, Tarakeshwar & Hahn, 2001) in Pakistan (Khan & Watson, 2006) and in the United Kingdom (Lewis, Maltby & Day, 2005), only two published articles were found that documented the development of the instrument with psychometric statistics. The first record of the instrument was published in 1998 with the next publication 13 years later (Pargament, Feuille & Burdzy, 2011; Pargament, Smith, Koenig & Perez, 1998). According to the numerous researchers who have used the Brief RCOPE, it has demonstrated good internal consistency across different samples, among which were cardiac surgery patients (Ai, Tice, Kronfol & Bolling, 2009, African American women with a history of partner violence (Bradley, Schwartz & Kaslow, 2005), cancer patients (Cole, 2005; Sherman et al., 2005), a community sample of U. K. adults (Lewis, Maltby & Day, 2005), and older adults in residential care (Schanowitz & Nicassio, 2006).

The Positive Religious Coping Subscale (PRC) (7 items) has had an alpha range of 0.67 to 0.94 across several studies. It is important to note that some of the studies used a seven point Likert scale instead of the four point scale and when the scales were used internationally, written translation of the scales to other languages were performed. Good concurrent validity has been demonstrated with both subscales (Pargament, Feuille & Burdzy, 2011). As might be expected, the PRC is most strongly and consistently related to measures of positive psychological and spiritual well-being constructs. The PRC is sometimes inversely related to negative constructs such as depression and ill health. Concurrent validity was reported as good. Cross sectional studies were conducted and it was found that PRC was significantly and positively

correlated with well-being constructs. Cronbach's alpha for the current study is 0.96 and the score range can be seen in Table one.

The Negative Religious Coping Subscale (NRC) (7 items) alphas were generally lower than those for the PRC subscale, ranging from 0.60 to 0.90 and the median alpha was reported as 0.81 (Pargament, Feuille & Burdzy, 2011). Cronbach's alpha for the sample of the current study was 0.97. Good concurrent validity has been demonstrated. Accordingly, NRC generally behaves in the opposite manner than the PRC. The NRC is consistently related to indicators of poor functioning, such as anxiety, depression, post-traumatic stress disorder symptoms, negative affect, and pain. However, NRC is occasionally associated with constructs representing well-being, though when such a correlation is significant, it is usually negative. In several cross sectional studies (Pargament, Feuille & Burdzy, 2011), the NRC was significantly and positively correlated with indicators of poor functioning.

The second published report (Pargament, Feuille & Burdzy, 2011) regarding the use and continued standing of the Brief RCOPE provided comprehensive psychometric information and an update on the performance of the tool. In addition to these important facts, the following was also addressed: only two studies were found examining the predictive validity of the Brief RCOPE. The studies provided support for the capacity of PRC and NRC to predict greater well-being and poorer adjustment respectively, over time. There was evidence of incremental validity of the PRC in predicting well-being after controlling for age, and gender, as well as a number of secular variables, including race, financial worries, having children, and other psychosocial constructs. Several studies supported the incremental validity of the NRC scale and suggested that the

NRC uniquely predicted outcomes even after controlling for secular variables and indicators of general religiousness.

Overall, it is agreed that the brevity of the Brief RCOPE is its greatest strength and it is its greatest weakness. The Brief RCOPE does not offer an extensive look into many methods of religious coping. However, it is a good at what it was intended to do: assess religious methods of coping in an efficient, psychometrically sound and theoretical manner.

The Multidimensional Sexual Self Concept Questionnaire (MSSCQ). (Snell, 1998, 2001; Snell, Fisher & Schuh, 1992). Two subscales of the MSSCQ were used in this study; each subscale used a five-point Likert scale. The Likert scale ranged from 0 to 4 with (0) indicating that an item is "not at all characteristic of me"; (1) "slightly characteristic of me"; (2) "somewhat characteristic of me"; (3) "moderately characteristic of me"; and (4) "very characteristic of me". In order to create subscale scores, items on each subscale are averaged, so that higher scores corresponded to greater amounts of the relevant subscale tendency. The MSSCQ has been used primarily with university undergraduate students.

All subscales of the MSSCQ demonstrated good internal consistency. The alpha coefficients were calculated by using a sample of 473 participants recruited from lower division psychology courses at a small Midwestern university. Cronbach's 'alphas calculated for young women on the 20 subscales of the MSSCQ ranged from 0.63 (Motivation to Avoid Risky Sex Subscale) to 0.93 (Sexual Pre-occupation Subscale).

Evidence of validity was found among university students when the MSSCQ subscales were associated in predictable ways to women's reported contraceptive

behavior/use. Women's long-term effective contraceptive use was negatively associated with the following subscales: sexual fear, sexual depression, and internal sexual control; and positively associated with sexual self-efficacy, sexual assertiveness, sexual motivation, sexual-esteem, sexual satisfaction, and sexual self-schema. Women reported greater motivation to avoid risky sexual behavior, and fear of sexual relations, which is important given that the virus that causes cervical cancer results from risky behavior and contraction of the human papilloma virus. In the current study sexual self-concept was operationalized with the measurement of sexual-esteem and sexual satisfaction.

The Sexual-Esteem Subscale (5 items) defined sexual-esteem 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. The scale contained five items. Higher scores corresponded to greater amounts of the subscale tendency. The Cronbach's alpha coefficient was reported as 0.89 (Snell, 2001). Cronbach's alpha for the current study was 0.97. See Table one to view the subscale score range.

The Sexual-Satisfaction Subscale (5 items) defined sexual satisfaction as a tendency to be highly satisfied with the sexual aspects of one's life. The subscale contained five items and was scored as explained above. Higher scores corresponded to greater amounts of the subscale tendency. Cronbach's alpha coefficient has been reported as 0.91 (Snell, 2001). Construct validity has been established through research (Snell, 1995), which found both of the subscales to be related in predictable

ways to female contraceptive behavior. Cronbach's alpha for the current study was 0.97. The subscale score range can be seen in Table one.

The Socially Desirable Response Set (SDRS – 5) (5 items) (Hays, Hayashi & Stewart, 1989). The SDRS-5 contained 5 items and covered the most common concerns of clinicians who relied on self–reported data: social desirability pressure, perceived importance of looking and sounding good, and being approved of as an important part of self-presentation. The SDRS-5 was used as a control variable in this study to determine the extent to which social desirability impacted responses to sensitive questions (religious coping and sexual self-concept). The items were derived from the Marlowe-Crowne (MC) scale as an 11 item short form measure developed from the 33 item MC. The five items that yielded the highest correlations to each other were chosen to be a part of the SDRS-5 (Hays, Hayashi & Stewart, 1989). The authors reported further that the instrument was tested with two samples: 614 outpatients of medical providers who participated in pilot studies for the Medical Outcomes Study (Stewart, Hays, & Ware, 1988) and 3053 outpatients of medical and mental health providers in the Medical Outcomes Longitudinal Study. Average age was 47 years and 62% were female with an average education level reported as 13 years. Alpha reliability estimates were 0.66 and 0.68, respectively. One month test–retest reliability was 0.75 in a sample of 75 older adults, obtained via a Pearson product–moment correlation of scores at the two time points. Thus, reliability of SDRS-5 approximates the 0.70 standard for social desirability scales. No validity reports were found. The Cronbach's alpha for the current study sample was 0.62 and the scale score range can be seen in Table one.

Table 1. Instrument Statistics

Instrument	Rating Scale	Potential Range	Study Range	Score Mean (SD)	Scale Mean (SD)
CAPS-Focused Subscale (α = .94)	1-5	10- 50	10-50	37.4 (7.15)	3.72 (.02)
CAPS-Processing Subscale (α = .86)	1-5	6-30	10-30	22.15 (3.94)	3.69 (.01)
Brief RCOPE-Positive Subscale (α = 0.96)	1-4	7-28	7-28	14.04 (7.1)	1.97 (.02)
Brief RCOPE-Negative Subscale (α = 0.97)	1-4	7-28	7-28	10.4 (5.8)	1.47 (.01)
MSSCQ Sexual-esteem Subscale (α = 0.97)	1-5	5-25	8-21	15.17 (6.4)	3.03 (.32)
MSSCQ Sexual Satisfaction Subscale (α = 0.97)	1-5	5-25	5-16	9.67 (6.7}	1.93 (.01)
SDRS-5 (α = 0.62)	1-5	5-25	13-21	17.1 (3.68)	2.85 (.87)

Data Collection Procedures

Advertisements and/or Invitations to join the research study were distributed electronically in the National Cervical Cancer Coalition (NCCC) and the Michigan Cancer Consortium (MCC) newsletters. The newsletters were distributed to over 1500

National and State Cancer Control Partners and to the Breast and Cervical Cancer Control Program consultants and Coordinators. Conducting research utilizing an online format was chosen because of the opportunity for global reach and potential access to a larger sample with faster response rates, less data processing and lower costs. More importantly, it was conjectured that the internet would convey a sense of social distance (Lyons, Cude, Lawrence & Gutter, 2005) to women, who have experienced cervical cancer and are often reluctant to talk about the experience (Cleary & Hegarty, 2011;Herzog & Wright, 2007; Sevin, 1999). Moreover, self-disclosure has been noted to increase when people used web-based surveys, particularly while communicating sensitive health issues (e.g. sexual satisfaction, religious coping) (Granello & Wheaton, 2004).

The Cervical Cancer Questionnaire was placed on SurveyMonkey, an online web survey development and host company. Research participants were recruited by electronic advertisement and invitation. The electronic advertisement/invitation included a link that connected participants to the questionnaire. The link opened to an information page that explained the purpose of the research study, value of participation, procedures to follow during participation, how long it would take to complete the questionnaire, assurance of anonymity and confidentiality. Consent to participate was confirmed by progression to the information sheet and completion of the questionnaire. Data collection was performed by the survey host company and the data was exported to the Statistical Package for the Social Sciences 20.0 (SPSS).

An incentive (32" flat screen television) was offered for taking part in the research study to the first 100 participants who wished to participate.

Data Management and Preliminary Analyses

Responses from SurveyMonkey were downloaded as Excel files and converted to an SPSS database file. SPSS was used for all subsequent analyses. Few responses were missing, partly because Zoom Panel (an additional service provided by SurveyMonkey) requires respondents to answer each question before moving on. Preliminary work related to cleaning and screening the data was done prior to analyses. Evaluating missing data was important. Following the electronic collection of the research data, it was exported from the online host into IBM SPSS version 20.0. Evaluation involved identifying missing data, identifying the cause, and/or pattern and imputing values where appropriate. Cases with outliers were examined and either dropped or values were transformed if they violated statistical assumptions.

A detailed descriptive analysis of all quantitative data was performed, involving the summarization of data and the use of inferential and graphical exploratory data analytic techniques. The information obtained from this preliminary exploration was used to describe univariate and bivariate sample distributions of the data, identify the interrelationships between variables and checks for violation of assumptions underlying identified statistical techniques. Preliminary analysis examined population representation of the sample because of exclusions or dropouts, and patterns of missing data.

Data Processing and Analysis

Preliminary Data Processing

Prior to the multivariate analyses the four coping subscales, the two sexual self-concept subscales, and the social desirability scale were computed as directed by scale authors. Race/ethnicity data were converted to a dichotomous variable (women of color and White non-Hispanic) was created because over 80% of respondents reported being White, non-Hispanic. In addition to a subjective question on health, another self-reported measure was created consisting of the number of diseases (other than cervical cancer) each respondent reported (including those written in under "Other").

Based on reported cancer treatments, a 10-point scale was developed to clarify the extent of treatment modalities ranging from 0= no treatment, 1=laser, cryosurgery or cauterization, 2=biopsy only, 3= biopsy plus laser, cryosurgery or cauterization, 4=total hysterectomy, 5=total hysterectomy plus biopsy, or laser or cryosurgery or cauterization, 6=chemotherapy only, 7=radiation therapy, 8=chemotherapy and radiation therapy, to 9=total hysterectomy, chemotherapy and/or radiation therapy, and 10=other was a final category that included multiple modalities beyond those rated as "9". Number of months in treatment was computed as the difference between reported dates of starting and ending treatment. Time since treatment began was computed based on reported treatment start date.

Data Analysis by Aims and Hypotheses

Aim 1: Examine the associations among cervical cancer treatment (surgery, radiation therapy, chemotherapy and combinations), demographic variables (time

since treatment began, cervical cancer stage, age, race, health status [perception and number of diseases] and SES [education and income]), cognitive coping (focused and processing) and religious coping (positive and negative) of women, who have been diagnosed with cervical cancer.

H1a: There are significant differences in health status, time in treatment (months), cognitive coping and religious coping among women, who have experienced treatment for non-invasive and invasive cervical cancer.

Independent-sample's *t*-tests were performed to determine whether there were significant differences between the women with non-invasive and invasive cervical cancer.

H1b: Time since treatment began is associated with cognitive and religious coping of women, who have experienced cervical cancer treatment.

Pearson's *r* correlations were conducted to identify associations between time since treatment began and coping (cognitive and religious).

H1c: Time since treatment began is associated with cognitive and religious coping after controlling for age, education, income and race/eth of women, who have experienced cervical cancer treatment.

Partial correlations were performed to identify associations between time since treatment began and coping (cognitive and religious) after controlling for select demographics.

H1d: There is a positive association between health status and cognitive and religious coping of women, who have experienced cervical cancer.

Pearson *r* correlations were conducted between health status (perception and number of diseases) and coping (cognitive and religious).

Aim 2: Examine the associations among demographic variables (time since treatment began, cervical cancer stage, age, race, health status [perception and number of diseases] and SES [education and income]), cognitive coping (focused and processing), religious coping (positive and negative) and sexual self-concept (sexual-esteem and sexual satisfaction) of women, who have been diagnosed with cervical cancer.

H2a: Age, education, income and health status (perception and number of diseases) is associated with cognitive coping, religious coping and sexual self-concept of women, who have experienced cervical cancer treatment.

Prior to testing the specific hypotheses a partial correlation analyses among all study variables were performed using Pearson's r, Spearman rho and Kendall's tau correlations. Pearson r correlations were performed between health status, coping and sexual self-concept.

H2b: There will be significant differences between coping (cognitive and religious) and sexual self-concept (sexual-esteem and sexual satisfaction) of White-non Hispanic women and women of color, who have experienced cervical cancer treatment.

Independent t-tests were performed to determine if there were significant differences between White non-Hispanic women and Women of color.

H2c: Demographic variables, cognitive coping and religious coping will predict variability in sexual self-concept.

Stepwise regression analysis was performed to predict variability in sexual self-concept.

Aim 3: Examine whether the relationship between religious and cognitive coping and sexual self-concept varies by race and education.

H3a: The relationship between religious coping and sexual self-concept will vary by race/ethnicity of women, who have experienced cervical cancer treatment.

Mediation analysis was performed.

H3b: the relationship between religious coping and sexual self-concept will vary by education of women, who have experienced cervical cancer treatment.

Mediation analysis was performed.

H3c: The relationship between cognitive coping and sexual self-concept will vary by race/ethnicity of women, who have experienced cervical cancer treatment.

This hypothesis was not examined because there was no relationship between race/ethnicity and sexual self-concept in H3a.

H3d: The relationship between cognitive coping and sexual self-concept will vary by education of women, who have experienced cervical cancer treatment.

This hypothesis was not examined because there was no relationship between education and sexual self-concept in H3b.

Chapter 4

Results

The purpose of this research is to examine associations among cervical cancer treatment (e.g. surgery, radiation therapy, chemotherapy and combinations), select demographic variables (e.g. time since treatment began, cervical cancer stage, age, race, health status [e.g. perception and number of diseases], SES [education and income]), coping (e.g. cognitive, religious coping), and sexual self-concept (e.g. sexual esteem, sexual satisfaction). The purpose of this chapter is to describe the demographic data of the study sample and the results of data analysis, organized according to the aims and hypotheses.

Demographic Data

A total of 99 participants began the questionnaire. Data from four participants were discarded because their scores on the Socially Desirable Response Scale-5 (SDRS-5) were four or above out of a score range of one to five points, with a higher score indicating more socially desirable answers (Hays, Hayashi & Stewart, 1989). One participant was dropped because cervical cancer treatment was documented as being received outside the U.S. Out of the remaining total of 94 participants, 66 participants completed the entire questionnaire and the full set of instruments. Twenty eight women only completed the demographic tool. Due to the extensive missing data from critical variables, these women's data were not used in the full analysis. Chi-square tests were conducted to analyze differences between respondents who completed the entire survey set and those who had only completed the demographic tool. No significant

differences were noted between the two groups on age (p = .245), education (p = .294) and income (p = .83).

Demographic characteristics were obtained through completion of a self-reported demographic measurement tool. The largest (56.1%) category of women were between

Table 2. ***Demographic Characteristics***	**Frequency(Percent)**
Age (n = 66)	
20-30 years	10 (15.1%)
31-40 years	18 (27.3%)
41-50 years	19 (28.8%)
51-60 years	11 (16.7%)
61-70+years	8 (12.1%)
Race or Ethnicity (n = 66)	
African American	2 (3.0)
Non-Hispanic White	55 (83.3)
Hispanic-Latino White	6 (9.1)
American Indian/Alaska Native	1 (1.5)
Mixed race/ethnicity	2 (3.0)
Education (n= 66)	
Less than 12th grade	2 (3.0)
High School Graduate	18(27.3)
Some College-Associate Degree	22(33.4)
Bachelor Degree	16(24.2)
Masters Degree	6 (9.1)
Doctorate	2(3.0)
Income (n = 66)	
Less than $20,000	12(18.2)
$20,000 - $40,000	19(28.8)
$40,000 - $80,000	23(34.8)
$80,000 - $100,000+	12(18.2)
Religious Affiliation (n = 62)	
Protestant	20(32.2)
None	27(43.5)
Roman Catholic	8(12.9)
Jewish	1(1.6)
Other (e.g., Greek Orthodox, Mormon)	6(9.6)

Health Status (Global General Perception) (n =66)	
Excellent	7(10.6)
Very Good	22(33.3)
Good	21(31.8)
Fair	11(16.7)
Poor	5(7.6)
Sexual Orientation (n=65)	
Heterosexual	59 (90.7)
Homosexual	6 (9.2)
Relationship status (n = 65)	
Single with same sex partner	4(6.2)
Single with Opposite sex partner	6(9.2
Married to same sex partner	2(3.1)
Married to Opposite sex partner	33(50.8)
Single/Widowed/Divorced	20(30.7)
Sexual activity Status (n = 66)	
Yes	38(57.5)
No	28(42.4)
Sexually Hurt/Trauma (n =21)	
Raped in the past	10(15.5)
Sexually Abused in the past	11(16.9)
None	44(67.7)
Missinng	1(1.5)

the ages of 31 and 50 years old. More than a quarter (28.8%) of the women in the study reported they were in the age range of 51 to 70 or older. Most women (83.3%) in the study were White, non-Hispanic and had at least a high school diploma (97%). Women of color (all others) comprised 16.6% of the sample, of whom only 3.0% identified themselves as African American and the remaining 13 women of color identified themselves as Hispanic, American Indian/Alaska Native and Mixed race/ethnicity. The majority of White women in the current study's sample were in the 30 to 50 year old age-range and the majority of women of color ranged in age from 50 to 70 years of age. Over two-thirds (70%) of the women had some college or a college degree and reported an annual income of more than $35,000 (see Table 2).

The majority of the participants (88%) reported learning about the research

study through the NCCC advertisement and a subsidiary of survey monkey, Zoom panel, which distributed the advertisement nationwide. Of the women who did respond to the study incentive (raffle for flat screen TV), they appeared to be responding from throughout the United States, because the zip codes in the return emails were spread nationwide (e.g. California, 92804, Nebraska, 68328, Iowa, 52769, Wisconsin, 53806, Michigan, 48204, Texas, 79601, Georgia, 30132, Maryland, 21230, Virginia, 24266, Pennsylvania, 16105, Massachusetts, 02145, New York, 12550).

Medical History and Cancer Related Demographic Data

Half of the respondents reported no medical conditions (50%, N = 33). Of those who did report a health condition, the most common conditions reported were high blood pressure (24% n=16), depression (23%, n=15), anxiety (23%, n=15), diabetes and arthritis. Similarly, women were taking medications for high blood pressure (23% n=15), depression, anxiety, diabetes and arthritis (see Table 3).

Table 3. ***Medical History***

Do you have the following diseases?	No. of Women*
High Blood Pressure	16
Heart Disease	2
Diabetes	13
Arthritis	10
Kidney Failure	1
Depression	15
Anxiety	15
No diseases	33
Do you take medications for:	
High Blood Pressure	15
Heart Disease	2
Diabetes	7
Arthritis	4
Kidney Disease	1
Depression	11
Anxiety	10
No prescribed medication taken	38

*Totals and percentages are not indicated, and numbers may sum to more than 66 as multiple responses were allowed.

Cancer Stage

Well over half of the women, n=34 (62.9%) in the study (non-Hispanic White women and women of color) reported being diagnosed at non-invasive (also known as precancerous) stage 0 and invasive stage I (see Table four) and were in the 31-50 year age range. Of the 34 women in stage 0 and stage I, five (9.2%) were women of color diagnosed at non-invasive stage 0 and one (1.8%) woman of color was diagnosed at invasive stage I. The remaining 28 (51.8%) women diagnosed at stage 0 and stage I was non-Hispanic White women. Six (11.1%) non-Hispanic White women reported being diagnosed at stage IV and in the age-range of 50 to 70 plus years. Only three (5.5%) women of color were diagnosed at stage IV and two (3.7%) of these women reported being in the age-range of 50 to 70 years. The remaining two (3.7%) women of color were in stage II. There were 9.2% (n=6) women that reported being homosexual and all but two of the women were diagnosed with early stage

cervical cancer.

Table 4. *Cancer Stage*	
***Cancer Stage* (N=66)**	**Frequency (Percent)**
Non-invasive Stage	
Stage 0	23(34.8)
Invasive Stage	
Stage I	11(16.6)
Stage II	8(12.1)
Stage III	3(4.5)
Stage IV	9(13.6)
Don't know	12(18.1)
Total	66(100)

Cervical Cancer Treatment

Surgical intervention was reported in the current study as the most frequent treatment (82%) received for cervical cancer and typically occurred during the precancerous and invasive stage I of cancer. Total hysterectomy was the most prevalent (46.9%) type of surgical intervention with laser, cryosurgery, biopsy and other types of surgery identified less often. Radiation and chemotherapy, typically used in advanced stages of cervical cancer, were the least reported treatment interventions (see Table 5).

Table 5. ***Cervical Cancer Treatment Received***

Type of Treatment (N=66)	Frequency (Percent)
Laser, Cryosurgery, Cauterization	12(18.2%)
Cone Biopsy	9(13.6%)
Cone Biopsy, Laser, Cryosurgery and Cauterization	4(6.1%)
Total Abdominal Hysterectomy (TAH)	19(28.8%)
TAH plus Cone Biopsy, Laser, Cryosurgery, Cauterization	7(10.6%)
Chemotherapy only	2(3%)
Radiation Therapy only	2(3%)
Chemotherapy and Radiation Therapy	2(3%)
TAH, Chemotherapy, and Radiation Therapy	5(7.6%)
Other	3(4.5%)

Symptoms Before and After Treatment

Women reported having experienced more symptoms after treatment for cervical cancer than was experienced prior to diagnosis and treatment. Low sex drive was reported as the most frequent symptom experienced following treatment across all forms of treatment modalities, while vaginal dryness was experienced most frequently following total hysterectomy and radiation therapy. An unexpected finding was women who were treated with surgery reported the largest number of symptoms following treatment compared to the other treatment modalities. Despite the overall experiences related to symptoms after treatment, some women did report improvement related to a few symptoms (see Table 6). Finally, 61 of the women (92.4%) reported having ever been sexually active. Only 38 women (58%) reported they were both, sexually active and experienced symptoms after cervical cancer treatment. Twenty-eight women (42%) were not sexually active, but also experienced symptoms after treatment. An ANOVA was conducted to identify whether there was a significant difference between the women who experienced symptoms and were sexually active and the women who experienced symptoms and were not sexually

active. The results were not significant (1, 64; F= 3.204; p=.078), but they were in an unexpected direction. Women who were sexually active had more symptoms than women who were not sexually active. It may be that the women who were not sexually active were unaware of potential symptoms. Meaning that actual sexual activity may have exacerbated the symptoms.

Table 6. Symptoms Before and After Treatment

	Before	After
Symptom	**Response Number***	**Response Number***
Pain	0	11
Vaginal Dryness	12	15
Vaginal Bleeding	18	4
Vaginal Tightness	3	7
Low Sex Drive	8	16
No Sex Drive	5	6
Unable to Climax	8	5
Fear	0	6
Sexual Dissatisfaction	9	6
No Problems	36	28

*Totals and percentages are not indicated, and numbers may sum to more than 66 as multiple responses were allowed.

Analyses by Aim and Hypotheses

Study aims and hypotheses sought to examine associations among cervical cancer treatment (e.g. surgery, radiation therapy, chemotherapy and combinations), select demographic variables (e.g. time since treatment began, cervical cancer stage, age, race, health status [perception, number of diseases], SES [education and income]),

coping (e.g. cognitive coping, religious coping), and sexual self-concept (e.g. sexual-esteem, sexual satisfaction).

Aim 1: Examine the associations among cervical cancer treatment, demographic variables, cognitive coping and religious coping of women who have been diagnosed with cervical cancer.

H1a: There are significant differences in health status, time in treatment, cognitive and religious coping among women, who have experienced treatment for non-invasive and invasive cervical cancer.

H1b: Time since treatment began is associated with cognitive and religious coping of women, who have experienced cervical cancer treatment.

H1c: Time since treatment began is associated with cognitive and religious coping after controlling for age, education, income, and race/ethnicity of women, who have experienced cervical cancer treatment.

H1d: There is a positive association between heath status and cognitive coping and religious coping of women, who have experienced cervical cancer treatment.

Associations Among Focal, Contextual and Coping Variables and Four Hypotheses

Most of the four hypotheses for Aim 1 were partially supported.

Hypothesis 1a was partially supported. Independent t-tests were conducted to compare invasive and non-invasive group scores related to the coping subscales, health status, and time in treatment. Results of the comparison of means were all non-significant with the exception of the Brief RCOPE-positive which had a significant difference between

the related invasive and non-invasive groups (see Table 7). Women in the invasive cervical cancer treatment group used positive religious coping significantly more than women in the non-invasive cervical cancer treatment group (t = 2.139, p = 0.036). None of the other variables were significantly different between the two groups.

Table 7. Mean Response and Differences between Noninvasive and Invasive Groups

Variable	Invasive Scale Mean (SD)	Non-invasive Scale Mean (SD)	*t*-test (df)	*p*-value
Health Status (subjective, objective)	2.93 (1.18) n=43	2.48 (0.85) n=23	1.62 (66)	0.110
Time in Treatment (months in treatment)	6.97 (8.18) n=38	6.10 (7.78) n1	0.40 (59)	0.689
CAPS-focused	36.49 (7.19) n=43	38.78 (6.87) n=23	1.25 (66)	0.215
CAPS-processing	22.07 (4.29) n=43	22.30 (3.27) n=23	0.23 (66)	0.820
Brief RCOPE-positive	15.27 (7.09) n=43	11.38 (6.64) n=22	2.14 (65)	0.036*
Brief RCOPE-negative	10.58 (6.45) n=43	9.71 (4.55) n=21	0.55 (64)	0.583

Hypothesis 1b was partially supported. Pearson's *r* correlations were conducted to determine an association between time since treatment began and cognitive (focused and processing) and religious (positive and negative) coping of

women, who have experienced cervical cancer. There was a significant negative correlation between time since treatment began and cognitive coping-focused subscale(r = -.36, p = .006) and cognitive coping-processing subscale (r = *-.32, p = 0.019*). Overall, the further women were from the time their treatment began, the less cognitive coping was used. There was no relationship to religious coping (see Table 8).

Table 8. Time Since Treatment Began and Coping (cognitive and religious)

	CAPS Focused	CAPS Processing	Brief RCOPE Positive	Brief RCOPE Negative
Time Since Treatment Began	-0.36**	-0.32*	-0.20	0.05

** Correlation is significant at the 0.01 level (2-tailed).

*Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 1c was partially supported; cognitive coping-focused subscale and religious coping-positive religious subscale were significantly and negatively related to the time that passed since treatment began (see Table 9). The differences between this result and the result in Hypothesis 1b indicated that a portion of the significant associations revealed in Hypothesis 1b were due to the independent variables (age, education, income and race).

Table 9. Time Since Treatment Began and Coping (cognitive and religious) before and after Controlling for Age, SES (e.g. education, income) and Race/Ethnicity

Variable	CAPS-Focused	CAPS-Processing	Brief RCOPE-Positive	Brief RCOPE-Negative
Time since treatment Began	**-0.36****	**-0.32***	-0.20	-0.05
Time since treatment began controlling for age, race, SES	**-0.28***	-0.26	**-0.28***	-0.01

*Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

When demographic variables were controlled or removed, the relationship between 'time since treatment began' and CAPS-processing weakened, but the relationship was strengthened for positive religious coping (see Table 9).

Hypothesis 1d was partially supported. Health status (perception-subjective) was significantly and negatively related to cognitive coping (focused and processing), but not positive or negative religious coping. The more objective measure of health status-(number of diseases) was significantly and positively associated to negative religious coping as seen in Table 10.

Table 10. Health Status and Coping (cognitive and religious)

Variables	CAPS Focused	CAPS Processing	Brief RCOPE Positive	Brief RCOPE Negative
Health Status	-0.39**	-0.47**	0.01	0.09
Number of Diseases	-0.19	-0.22	0.07	0.33**

Additional Analyses

Given that radiation treatment has been shown to contribute to the most significant morbidity post treatment (Andersen, 2000; Frumovitz et al., 2005; Jensen et al., 2003, 2004), an ANOVA by treatment group (radiation versus no radiation) was performed (see Table 11). No significant differences were noted in Table 11 by treatment type (no radiation versus radiation), coping (cognitive and religious) and sexual self-concept (sexual-esteem and sexual satisfaction). While there were no significant findings, the means for women, who had radiation showed slightly higher means compared to women, who did not have radiation, except for the findings for sexual satisfaction.

Table 11. Treatment Type, Coping (cognitive and religious), and Sexual Self-Concept (sexual-esteem and sexual satisfaction)

	Treatment	N	Mean	F	Sig.
CAPS-focused	No Radiation Radiation	54 12	37.0535 38.3333	.314	.577
CAPS-processing	No Radiation Radiation	54 12	22.0370 22.6667	.248	.620
Brief RCOPE-positive	No Radiation Radiation	53 12	13.2642 17.0000	2.758	.102
Brief RCOPE-negative	No Radiation Radiation	52 12	10.0192 11.5000	.615	.436
MSSCQ-sexual-esteem	No Radiation Radiation	54 12	3.2222 3.2833	.022	.883
MSSCQ-sexual satisfaction	No Radiation Radiation	54 12	2.9889 2.6833	.508	.479

Aim 2: Examine the associations among demographic variables, cognitive coping, religious coping and sexual self-concept of women who have been diagnosed with cervical cancer.

H2a: Age, education, income and health status is associated with cognitive coping, religious coping and sexual self-concept of women, who have experienced cervical cancer treatment.

H2b: There will be significant differences between coping (cognitive and religious) and sexual self-concept of White, non-Hispanic women and women of color, who have experienced cervical cancer treatment.

H2c: Demographic variables, cognitive coping and religious coping will predict variability in sexual self-concept.

Associations among all study variables and Three Hypotheses

Of the three hypotheses for Aim 2, two were partially supported and one was not

supported. Prior to testing the specific hypotheses a partial correlation analysis among all study variables (see Table 12) was performed using Pearson *r*, Spearman's rho and Kendall's tau correlation statistics. Significant correlations in the current study suggested that cancer stage was positively correlated with number of cancer treatments, positive religious coping, and health status (perception). Number of cancer treatments was positively correlated with cancer stage and positive religious coping. Unexpectedly, there were no significant correlations between all of the other variables and race, and all of the other variables and age. While education as expected was correlated with income level, it was not correlated with any other variables. Cognitive coping-focused was significantly and positively correlated with several important variables. For example, cognitive coping-focused was positively correlated with positive religious coping, sexual-esteem and sexual satisfaction, and negatively correlated with health status (perception) and number of diseases (e.g. comorbid conditions). Cognitive coping-processing was similarly correlated with all of the same variables; it was correlated positively with positive religious coping, sexual self-esteem and sexual satisfaction and negatively correlated with health status (perception and number of diseases. Meaning women who scored high on positive religious coping also scored high on negative religious coping. Sexual-esteem and sexual satisfaction were significantly correlated positively with both cognitive coping scales and negatively with health status-perception.

Positive religious coping was positively correlated with cancer stage and cancer treatment. It means that as the cancer stage and number or intensity of the treatments increased the women used more positive religious coping. Negative religious coping

was only significantly correlated with positive religious coping and surprisingly, it was in the positive direction. This means that women who used religious coping used both positive and negative coping strategies and that the variables are intercorrelated or the variables are not much different from one another. As expected, health status perception was negatively and significantly correlated with number of diseases.

Table 12. Associations among All Study Variables

Variable *M* (*SD*)	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Cancer Stage 2.33 (1.49)	-												
2. Cancer Treatment 4.09 (2.70)	.644**	-											
3. Age 3.83 (1.30)	.238	.165	-										
4 Education 5.47 (1.9)	-.150	-.096	.110	-									
5. Income 2.92 (1.53)	-.203	-.074	.079	.434**	-								
6. Coping-Focused 37.28 (7.11)	.008	.160	-.061	.200	.133	-							
7. Coping-Processing 22.15 (3.93)	.024	.150	-.055	.148	.155	.796**	-						
8. Religious Positive 13.95 (7.13)	.352**	.303*	.079	-.015	-.115	.259*	.316*	-					
9. Religious Negative 10.29 (5.87)	.053	.077	-.199	-.081	-.135	.218	.139	.453**	-				
10. Sexual-esteem 3.23 (1.28)	.140	-.043	.104	-.023	-.050	.384**	.371**	.032	.220	-			
11. Sexual Satisfaction 2.93 (1.33)	-.190	-.186	.152	- .013	.183	.427**	. 427**	.151	.135	.744**	-		
12. Health perception 2.93 (1.18)	.336*	.034	.179	-.159	-.213	-.417***	- .492**	-.079	-.077	-.348**	-.389**	-	
13. No. of Diseases	.033	.057	.106	-.090	-.229	-.281*	-.279*	.031	.200	-.012	-.178	-.481**	-
14. Race	.073	.185	.005	-.085	.031	.005	.069	.081	-.111	.039	.002	-.169	.041

* p < .05
** p< .01
***p<.001

Hypothesis H2a was only partially supported. The only significant results were the negative associations between health status perception and the cognitive coping scales (focused and processing) and the sexual self-concept scales (sexual-esteem and sexual satisfaction) (see Table 13). The better women perceived their health status; the less cognitive coping was used and women's sexual self-concept was worse. Objective health status (number of diseases) was not related to sexual self-concept (sexual-esteem and sexual satisfaction) but negatively related to cognitive coping (focused and processing). The number of diseases (health status) was not related to negative religious coping (.200). The more diseases (comorbidities) women had to contend with while enduring cervical cancer and treatment morbidity, the less their use of cognitive

Table 13. Associations among Demographic Variables (age, education, income, health status), Coping (cognitive and religious) and Sexual Self-Concept

Variables	CAPS Focused	CAPS Process	Brief RCOPE Positive	Brief RCOPE Negative	MSSCQ Sexual-esteem	MSSCQ Sexual Satisfaction
Age	-.061	-.055	.079	-.199	-.104	-.152
Education	.200	.148	-.015	-.081	.023	.013
Income	.133	.155	-.115	-.135	-.050	.183
Health Status perception	.-417 **	- .492**	- .079	-.077	- .348**	- .389**
Number of Diseases	-.281*	-.279*	.031	.200	-.012	-.178

** Correlation is significant at the 0.01 level (2-tailed).

*Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 2b was not supported (see Table 14). The t-values were very small and the p values were not significant.

Table 14. Comparison between Women of Color and White Women

Variables	Women of color & White women	N	Mean (SD)	T-value	P-value
CAPS-focused	Women of color White women	11 55	37.36 37.27	0.04	.969
CAPS-processing	Women of color White women	11 55	21.54 22.27	-0.56	.580
Brief R cope positive	Women of color White women	10 55	15.30 13.71	0.66	.521
Brief R cope negative	Women of color White women	10 54	11.80 10.01	0.88	.383
Sexual-esteem	Women of color White women	11 55	16.73 16.05	.315	.754
Sexual satisfaction	Women of color White women	11 55	9.64 9.67	-0.02	.987

In *Hypothesis 2c*, the stepwise regression analysis sought to predict sexual self-concept (sexual self-esteem and satisfaction, combined and separately) from selected demographic and coping variables. Initially a regression analysis was run with a combined scale (self-esteem and satisfaction) given the high correlation between the two scales (r = .744). No independent variables predicted sexual self-concept using this dependent variable. Given these findings, two distinct regression analyses were conducted. All variables were originally included in the analysis and the stepwise

process eliminated non-significant variables with each step of the process. In these final analyses, cognitive coping-focused predicted 38% of the variance in sexual-esteem and cognitive coping-processing predicted 43% of the variance in sexual satisfaction (see Table 15 and Table 16). No other demographic or religious coping variables predicted sexual self-concept.

Table 15. Stepwise Regression Analysis Predicting Sexual-Esteem

Variable	B	SE B	ß
Step 1			
CAPS-focused	.347	.104	.384**
Step 2 excluded non-significant variables			
HS	.227	NA	NS
CAPS-processing	.177	NA	NS
Note. R^2 = .384 for Step 1. R^2 = no change for Step 2; ** p <.01, NS non significant			

Table 16. Stepwise Regression Analysis Predicting Sexual Satisfaction

Variable	B	SE B	ß
Step 1			
CAPS-processing	.725	.192	.427***
Step 2 excluded non-significant variables			
HS	.236	NA	NS
CAPS-focused	.237	NA	NS
Note. R^2 = .427 for Step 1. R^2 = no change for Step 2; *** p <.001, NS non significant			

Aim 3: Mediation Analyses of Four Hypotheses

Aim 3: Examine whether the relationship between religious and cognitive coping and sexual self-concept varies by race and education.

H3a: Religious coping (positive and negative) will mediate the relationship between race/ethnicity and sexual self-concept (sexual-esteem and sexual satisfaction) of women, who have experienced cervical cancer treatment.

H3b: Religious coping (positive and negative) will mediate the relationship between education and sexual self-concept (sexual-esteem and sexual satisfaction) of women, who have experienced cervical cancer treatment.

H3c: Cognitive coping (focused and processing) will mediate the relationship between race/ethnicity and sexual self-concept (sexual-esteem and sexual satisfaction) of women, who have experienced cervical cancer treatment.

H3d: Cognitive coping (focused and processing) will mediate the relationship between education and sexual self-concept (sexual-esteem and sexual satisfaction) of women, who have experienced cervical cancer treatment.

Mediation analyses

The four mediation hypotheses included coping, which were measured by the two religious coping subscales (positive and negative) and sexual self-concept, which was also measured by two subscales (sexual-esteem and sexual satisfaction). Therefore, each hypothesis required four separate analyses; e.g., positive religious coping combined with sexual-esteem, positive religious coping combined with sexual satisfaction, negative religious coping combined with sexual-esteem, and negative religious coping combined with sexual satisfaction.

H3a was not supported Religious coping (positive and negative) will mediate between race/ethnicity and sexual self-concept (sexual-esteem, sexual satisfaction) of women, who have experienced cervical cancer treatment. The results of this analysis showed that the first condition for mediation was not met. To conduct mediation required that the dependent variable (two outcome variables) be regressed on the independent variable (race/ethnicity). If this step did not result in significant relations there was no relation to mediate and therefore, the mediation process was halted at the first step (Polit, 2010).

H3b was not supported. Religious coping (positive and negative) will mediate between education and sexual self-concept (sexual-esteem, sexual satisfaction) of women who have experienced cervical cancer treatment. The results of this analysis also showed that the first condition for mediation was not met (same as above). To conduct mediation required that the dependent variable (two outcome variables) be regressed on the independent variable (race/ethnicity). As stipulated above, if this step did not result in significant relations there was no relation to mediate and therefore, the mediation process was halted at the first step (Polit, 2010).

H3c was not supported. Cognitive coping (focused and processing) will mediate between race/ethnicity and sexual self-concept (sexual-esteem and sexual satisfaction) of women who have experienced cervical cancer treatment. This hypothesis was not examined because no relationship between race/ethnicity and sexual self-concept was identified in H3a (see above).

H3d was not supported. Cognitive coping (focused and processing) will mediate between education and sexual self-concept (sexual-esteem and sexual satisfaction) of women who have experienced cervical cancer treatment. This hypothesis was also not examined because no relationship between education and sexual self-concept was identified in H3b (see above).

Chapter 5

Discussion

The purpose of this study was to examine associations among cervical cancer treatment (e.g. surgery, radiation therapy, and chemotherapy), select demographic variables (e.g. time since treatment began, cervical cancer stage, age, race, health status [e.g. global general health perception-subjective and number of diseases-objective], SES [with education and income as a part of SES]), coping (e.g. cognitive coping, religious coping) and sexual self-concept (e.g. sexual esteem, sexual satisfaction). Mediation influences of coping between certain demographic variables and sexual self-concept were also explored related to women who were diagnosed and treated for cervical cancer. A discussion of the results and associations to existing literature are discussed in this chapter. Study strengths, as well as, limitations, practice and policy implications along with future research recommendations are also discussed.

The aims of the study were to: 1) examine associations among cervical cancer treatment, demographic variables demographic variables, cognitive coping and religious coping of women, who had been diagnosed with cervical cancer; 2) examine associations among demographic variables, cognitive coping, religious coping and sexual self-concept of women, who had been diagnosed with cervical cancer; and 3) Examine whether the relationship between religious and cognitive coping and sexual self-concept varies by race and education.

This study was the first to examine selected associations among cognitive and religious coping and sexual self-concept in women who had undergone cervical cancer treatment. To the author's knowledge, it is the first study to investigate women's sexual self-concept with both, heterosexual and homosexual women. No other study about

women's sexual self-concept was found that intentionally included homosexual and heterosexual women in the sample. Partial support for two of the three aims was found and six of the eleven hypotheses were partially supported. Unique to this study, the cognitive coping concepts were important predictors of sexual self-concept and important associations between the coping variables and selected demographics were found. For example, women in the invasive cervical cancer treatment group used positive religious coping significantly more than women in the non-invasive cervical cancer treatment group. Overall, the further women were from the time their treatment began, the less cognitive coping was used. Taken together, the findings suggest that both cognitive coping strategies (focused and processing) may influence sexual self-concept (esteem and satisfaction) in women after cervical cancer treatment. The findings further revealed similar support for the coping variables as prognostic factors of sexual self-concept (esteem and satisfaction) but the predictors varied by dependent variable (e.g. cognitive coping-focused predicted sexual esteem, while cognitive coping-processing predicted sexual satisfaction).

One of the primary features of this study was the geographic and racially diverse sample. Although the current sample was small (n = 66); it was diverse, both racially and in terms of sexual orientation. Heterosexual and homosexual women were included from across the nation, albeit in small numbers. The overall sample was comprised of 83% (n=55) White women and 17% (n=11) women of color that included only two women who reported their racial identity as African American/Black women. Notably, 72.7% (n=8) of the 11 women of color (self-identified as four Hispanic , one American Indian/Alaska Native, one African American, and two Mixed race) were

diagnosed in early stage (Stage 0 to stage II) cervical cancer. The remaining 27.2% (3) women of color (self-identified as one African American and two Hispanic) were diagnosed in stage IV also known as late staged (stage III and IV) invasive cervical cancer. All but two of the women who self- identified as homosexual had had early stage cervical cancer; two of the homosexual women did not know their stage.

Overall, close to 65 % of the women in the entire sample reported being diagnosed and treated for early stage cervical cancer (stage 0 to stage II). This result was lower than the national cervical cancer statistic of 85% (Waggoner, 2003). This is likely due to the convenience sampling process which may have attracted women who had more invasive cancer and possibly more concerns about sexual issues. This is somewhat supported by the fact that eighteen percent of women in the current study reported having been diagnosed with late stage cervical cancer (stage III and IV), which was a larger percentage compared to approximately 15% of women diagnosed nationally with late stage disease.

The current study's results were congruent with most cervical cancer literature regarding White women usually being diagnosed earlier in age than women of color (Coker, Du, Fang & Eggleston, 2006; Greimel, Winter, Kapp & Haas, 2009; Sawaya et al. 2001). Similar to the extant literature women of color in the current study were usually diagnosed at later ages (Hicks, Yap, Matthews & Parham, 2006). Surprisingly however, more White women in the current study compared to women of color were diagnosed with late stage cancer. In the literature for the last two to three decades White women generally received earlier diagnoses at earlier stages and ages and with better outcomes (Coker, Du, Fang & Eggleston, 2006; Shelton, Paturzo, Flannery &

Gregorio, 1992). This finding was not only surprising, but also confusing. It seemed confusing, especially since over two thirds (70%) of the women in the sample were college graduates, appeared to have fair to good income levels (though family sizes of the women with a particular income were unknown) and over 75% reported good to excellent health aside from the cancer diagnoses. Furthermore, only half of the women reported having additional co-morbidities. High blood pressure was the most commonly reported disease. Unlike the life-risking impact of co-morbidities that Brooks and her colleagues (2000b) uncovered involving more vulnerable women with cervical cancer, the current study sample of women were essentially healthy and less vulnerable. Notwithstanding family size information, it seemed reasonable to expect that all of the women had the means to have their cervical cancer identified early (Singh, Miller, Hankey & Edwards, 2004). Increased cervical cancer screening with a growing focus on the need for screening could have contributed to the amount of cervical cancer diagnosed among the women in the sample. The current study's incidence level of cervical cancer seemed greater than what would be expected among women possibly with means to prevent it. The finding could have been due to the small sample size and self-selection into the study. It was a finding that deserved further exploration.

Unexpectedly, the relationships between age, and race and several contextual variables (i.e. cancer treatment) were not found. Unlike the relationships to age commonly seen and discussed in the literature, few significant relationships to age were found and no relationships with race were found (Delaloye, Pampallona, Coucke & De Grandi, 1996; Mandelblatt et al., 1991; Sawaya et al., 2001). There was a non-significant relationship between age and cervical cancer stage. In the future, a larger

sample size could determine if the findings are due to sample size limits or another factor.

Cervical cancer treatment has been known to be influenced by age and race (Merrill, Merrill & Mayer,2000). A direct influence of age and an indirect influence of race and stage were shown to have an effect on the extent of treatment. Neither variable had an association with treatment in the current study. The sample characteristics of the current study (e.g. being younger, White and mostly diagnosed with early stage disease), no doubt influenced the study outcomes. Moreover, the non-significant findings in the current study likely reflected the result of a power issue linked to the small sample size and a convenient sampling strategy. The small sample size, particularly the limited number of women over the age of 50 (n = 19). It is also possible that the recruitment strategy (online) and survey process (online) might have restricted the sample to a younger group of women. Future research will need to incorporate a variety of sampling strategies and survey methodologies.

This study was one of only a few (Jensen et. Al., 2004; Pieterse et al., 2006) that compared sexual self-concept physical and sexual problems before and after cervical cancer treatment. Many studies have only explored such difficulties after treatment (Greimel, Winter, Kapp & Haas, 2009). As was expected and congruent with the findings by Jensen (2004) and Pieterse (2006), women in the current study experienced far more sexual problems after treatment than before treatment. Even more important, of the few studies that investigated these variables, none explored the combination of physical sexual problems along with measures of cognitive and religious coping and sexual self-concept. Several studies added aspects of the physical sexual

response cycle (e.g. desire, excitement, orgasm, resolution) in an attempt to operationalize female sexual self-concept or female sexuality (Andersen, Woods & Copeland, 1997; Carpenter, Andersen, Fowler & Maxwell, 2009; Greimel, Winter, Kapp & Haas, 2009; Juraskova et al., 2003; Levin et al., 2010; Lutgendorf et al. 2000), but no study used a holistic and comprehensive framework to study all of these aspects of women's sexuality . Moreover, only one of these studies was conducted solely with women who had had cervical cancer (Greimel, Winter, Kapp & Haas, 2009).

Treatment effects on various aspects of women's lives and sexual functioning were investigated in the Greimel et al. study, (2009). Findings revealed that close to 50% of the women reported they were not sexually active following treatment. The status was reported as being primarily due to not having been interested in sexual activity or not having an intimate partner. No information was reported on the rationale for women's lack of interest, so it was not known if their answer was unrelated to cancer treatments. The current study explored all of these variables as well. In contrast to earlier research, many women were sexually active despite having symptoms. What the women believed and felt and how they coped with the impact of cervical cancer treatment on their sexual functioning requires significantly more study. Moreover, the previous research included women with diverse gynecologic cancers of different stages and treatments combined in the same studies. Studies focused soley on women post cervical cancer treatment might uncover important links between sexual functioning and syptoms. A qualitative examination of these highly sensitive topics might uncover information for women's sexual health.

The findings in the current study related to women's use of religious coping seemed comparable to how the use was depicted in the literature among women with similar demographics. Even though cervical cancer is curable, the significant use of religion to cope observed in the invasive cancer group seemed reasonable given that invasive cancer could be lethal (Newman & Garner, 2005; Merrill, Merrill & Mayer, 2000) and if treated, might require more intrusive treatment (Herzog & Wright, 2007). The analyses revealed that positive religious coping was used significantly more by women in the invasive cervical cancer group compared to women in the non-invasive group (Table 7). Even women without a religious affiliation used positive religious coping. Of the 27 (43.5%) women who reported not practicing a religion, 15 (55.5%) reported having been diagnosed with non-invasive cervical cancer and 12 (44%) reported a diagnosis of invasive cervical cancer. Religious coping efforts are thought to bridge the person's orientation to outcomes though there has only been sparse empirical evidence of this (Pargament et al., 1990; Pargament et al., 1992). There seemed to be more evidence to the contrary, especially when not all forms of religion buffered the effects of stress (Pena & Frehill, 1998), or helped in one situation, but not others (Banthia, Moskowitz, Acree & Folkman, 2007) or exacerbated more stressors (Wagner & Rehfuss, 2008).

There was no evidence found in the literature of women of color being included in cognitive coping studies. Overall, there seemed to be less known in general about how people of color cope with adversity, most likely a result of not being included in research studies. An exception might be documentation related to religious coping, which usually indicate higher use primarily among African American and Hispanic women compared

to White women (Banthia, Moskowitz, Acree & Folkman, 2007; Bourjolly, 1998; Culver, Arena, Antoni & Carver, 2002). Support in the literature was been mixed regarding demographics of women related to cognitive coping. Usually cognitive coping was associated with being White, and having higher education and income (Diehl, Coyle & Labouvie-Vief, 1996; Schnoll, Harlow, Stolbach & Brandt, 1998).

An understanding and combined use of both, positive and negative religious coping and cognitive coping seemed logical, particularly in conflicting or confusing religious circumstances. Additionally, the context of a coping situation can be so fluid that what might be positive or effective coping at the onset of a situation could be entirely different later or even during the same process. It therefore, seemed very reasonable to expect an individual to have contradictory emotions, states of mind and behaviors and use combinations of coping strategies and processes if available. Consequently, it was surprising that the scores on both, positive and negative religious coping along with cognitive coping were lower than expected in the current study. It was understandable that women who contended with the physical, social and religious impact of cervical cancer, might use either or both, positive and negative religious coping, consciously or unconsciously (Davison, Darling & Norton, 1995). Although religious coping was believed to contain a level of complexity that was not a part of non-religious coping methods (Pargament, 1997) still, coping processes are similar in that both consist of a stressor, the coping context and a response to the situation by the stressed individual (Folkman & Moskowitz, 2004). Therefore, with the similarities in the coping processes and the seemingly multidimensionality of religious coping, the use of positive and negative religious coping in combination with one another seem rational.

Perhaps, with a larger sample or a purely diverse sample of women more can be learned about the combination, albeit contradictory nature of coping with cervical cancer could be uncovered; likely paralleling the unpredictable nature of life and more significant findings would emerge.

While over 40% of women reported not practicing a formalized religion, they still engaged in the use of religious coping. Practicing a particular religion is not a prerequisite to practicing religious coping, nor is the opposite true. Nevertheless, there could be many explanations for women's use of religious coping even though there was not an affiliation with a particular religion. It is well known that religion and women's sexuality is a very complicated issue in our society. More research is needed to better understand the impact of religion and religious coping in a group of women who have developed a serious illness that is caused by a stigmatized condition, like HPV and its links to cervical cancer.

The relationship between time since treatment began and coping of women who had cervical cancer was investigated by using Pearson product-moment correlation coefficient (Table 9). There was a significant negative correlation between time since treatment began and cognitive coping (focused and processing). The important implication was that coping was used less the further women were from the start of treatment. Future research will need to explore whether this implies successful adaptation or a diminished need. A limited amount of research has been conducted related to this important point (Bourjolly, 1998; Culver, Arena, Antoni & Carver, 2992; De Groot et al., 2005). More research is needed that utilizes a longitudinal design and follows women from the start of treatment to several years post treatment to determine

any fluctuations in coping processes. Moreover, in future research a diverse sample of women will help to understand the racial/ethnic and demographic influences on these results and could help predict a more suitable coping method that might help women to more successfully adapt after cervical cancer treatment. The women in the sample were primarily white, young middle-aged, well-educated and had good to excellent health and appeared to be more amenable to cognitive coping (Diehl, Coyle & Labouvie-Vief, 1996).

From the time since treatment began up to two years and sometimes beyond, has been thought to be a critical time for women recovering from cervical cancer and for their families (De Groot et al., 2005). Several evidence-based studies (Eisemann & Lalos, 1999) indicated that compared to women treated for other gynecologic and breast cancers, women treated for cervical cancer reported more often having experienced persistent difficulty throughout all survival stages of cervical cancer (e.g. acute, extended, permanent long-term). Yet there have been no consistent guidelines or standards of care formalized to assist women through the difficulty. Reportedly if women do not request help or volunteer information for any of the difficulty, important discussions concerning sexual self-concept would not take place (Horden, 2008). During the acute survival stage, younger women typically struggle the most with adjustment after treatment (Carpenter, Andersen, Fowler & Maxwell, 2009). It seems logical that great amounts of stress could affect how women responded to new stressors as well as their ability to adapt (Baum, Garofalo, Yali, 1999). Examining coping at various points in time following treatment could be a gateway to successfully helping women to develop better ways of coping with cervical cancer treatment. And

perhaps, buffer some of the stress generated by uncontrollable variables, like lowered SES.

Independent t-tests were performed to determine if there were significant differences related to coping and sexual self-concept between White women and women of color and the result was surprising. No significant differences were found, which was unexpected. The actual result was unforeseen because empirical studies have previously shown that compared to White women, women of color and in some instances, Black women compared to Hispanic and Asian women as well, experienced less distress after cancer treatments and less depressive symptoms (Culver, Arena, Antoni & Carver, 2002; Deimling et al., 2006). Furthermore, the researcher believed that a significant difference emphasizing women of color would have been revealed from the analysis based on having experienced how Black women have been able to survive and achieve despite a life impelled with environmental demands (e.g. unequal health care, economy, employment, education, community well-being, and legal system). Many times the demands seemed to tax or exceed Black women's adaptive capacity creating increased risk of disease (Schultz et al., 2000) and yet, a strong ability to retain self-respect and cope was still observed. Even though no significant results were revealed in the analysis, a majority of higher means were noted among the group of women of color compared to the group of White women. The implication of the higher means among women of color could indicate that significance was lessened by there being a small sample size. Additionally, a study conducted by Bourjolly (1998) that investigated differences in religious coping between Black and White women confirmed that Black women used religious coping more compared to White women.

This was true in their private and public use of religion. The Culver et al., (2002) study seemed to extend the Bourjolly (1998) findings by revealing that both, Black and Hispanic women used religious coping more compared to White women. Moreover, White women were noted to use humor more to cope than Black and Hispanic women. No previous studies were found that compared cognitive coping strategies between women of color and White women.

Two dimensions or components of sexual self-concept, sexual esteem and sexual satisfaction, were utilized in the current study to measure the concept. Since overall little research has been conducted that has included non-White participants, research related to sexual self-concept has not been an exception to this actuality. Nevertheless, there has been a recurrent notion in the literature, albeit limited, that has depicted a strong positive sexual self-concept motif measured by sexual esteem and sexual satisfaction for women of color.

Sexual self-concept (e.g. measured by sexual-esteem and sexual satisfaction) was the important outcome variable in the current study. Cognitive coping-focused predicted 38% of the variance in sexual esteem and cognitive coping–processing predicted 43% of the variance in sexual satisfaction. No other demographic or religious coping variables predicted sexual self-concept. Few studies have utilized a community based sample of middle aged adult women; most have focused on young adult white college students or adolescents (Impett & Tolman, 2006; Rostosky, Dekhtyar, Cupp & Anderman, 2008). Other research studies with adult female samples further led to the belief that women of color compared to White women have shown a tendency to report higher sexual self-concept with greater sexual satisfaction (McCabe & Taleporos, 2003)

and sexual-esteem (Twenge & Crocker, 2002), particularly following cancer treatment (Ganz et al., 1999; Ganz et al., 2003). The evidence from these studies and the researcher's experience helped create the expectation that significant differences existed between women of color and White women relative to cognitive coping, religious coping and sexual self-concept.

The association of women's sexual self-concept to cervical cancer treatment comes with great benefit and burden of cure and prolonged survival. Despite the phenomenal progress made in the treatment and cure of cervical cancer, the aftermath of most treatments have a profound effect on how women view themselves, their relationships, and their physical and psychosexual adjustment. Treatment for cervical cancer consists of surgery, radiation, chemotherapy and combinations. Problems common with all forms of treatment include pain, decreased sensitivity and sensation of tissues surrounding the genital area, decreased libido, shortening and stenosis of the vagina (Mouga, 2002). Radiation and multi-modal combinations of radiation (e.g. external and internal) with other treatment modalities have been thought to exercise the greatest burden for women following treatment (Juraskova et al., 2003) and problems have been short-term and long term. In addition to the radiation effects on sexual organs and tissues, adjacent organs (e.g. bladder, bowel) have suffered unintended exposure to the radiation, which compound psychosexual morbidity experienced by women. Life after radiation therapy have included altered bodily functions such as persistent low grade diarrhea, resulting in a hindrance to intimate relationships, travel complications and possibly social isolation (Herzog & Wright, 2007). Additionally, women have reported feeling unattractive, having a poorer body image and sexual-

esteem, a lost of femininity and for some, loss fertility and all that is represented by such a loss, sexually dissatisfied and in constant fear of metastasis or cancer recurrence (Cull et al., 1993; Herzog & Wright, 2007; Jensen et al., 2003). Of the women in the current study, who reported having radiation therapy treatment 66.6% were single with a partner or married and 50% reported being sexually active.

Based on the history of such morbidity following radiation treatment an ANOVA by treatment group (radiation versus no radiation) was performed to assess the significance of radiation treatments related to the women in the current study. There were no significant findings, which was not surprising since the sample of women who experienced radiation treatment was small. The means however, of women who received radiation indicated a slightly higher trend compared to women who did not receive radiation, with the exception of the findings for sexual self satisfaction (see Table 11). The results suggested the possibility of a diminished significance likely due to the sample size. It further signified the clinical significance of radiation treatments related to instructing clinical practice with women, who might have or have had radiation treatments.

There have been mixed empirical-based evidence regarding surgical treatments except related to radical hysterectomy with or without adjuvant chemotherapy or radiation therapy. Several researchers have indicated that problems following most simple surgical procedures with the above exception tended to have short-term effects overall, particularly on sexual function (Frumovitz et al., 2005; Greenwald & McCorkle, 2008; Grumann, Robertson, Hacker & Sommer, 2001). Moreover, some women have reported a neutral or enhancing effect on sexual function after surgery. Other

researchers have reported persistent long-term problems (Herzog & Wright, 2007; Pieterse et al., 2006). The symbolism that the uterus, cervix and childbearing hold for women, has been thought to commonly be overlooked and the impact of this is not frequently known or explored, despite its importance to women.

A majority of the women in the current sample reported having a surgical intervention as treatment for their cervical cancer. Surgical treatment included laser, cryosurgery, cone biopsy and treatment, cryosurgery, cauterization, loop electrosurgical excision procedure and hysterectomy. The greatest amount of difficulty was reported by women in the current study that had hysterectomies. It was not reported whether the hysterectomies were simple or radical hysterectomies. However, since the majority of the women had non-invasive cervical cancer and the disease primarily affects younger women, it is possible that most of the women were treated with simple hysterectomies and other less invasive treatments. Nevertheless, the majority of post treatment problems were reported by women in the current study sample, who had surgical intervention and this concurred with most of the literature that cite younger women with early stage disease experiencing the greatest amount of distress following treatment (Herzog & Wright, 2007; Wenzel et al., 2005). The problem that was reported the most frequently by women that had surgery, radiation therapy and chemotherapy was vaginal dryness, which was reported repeatedly in the literature as a major complaint of women following treatment (Jensen et al., 2004; Pieterse et al., 2006). Low sexual drive was reported by women in the current study across all treatment modalities the most frequently following the complaint of vaginal dryness and the complaint doubled after treatment compared to the level before treatment. There could be several explanations

for this finding with a primary explanation being distress/discomfort. Based on the commonality of this result more exploration might be helpful and enlightening. Pain and fear were the next complaints rendered the most by the women in the current study. This seemed reasonable since the women were diagnosed with cancer, which is commonly thought of as life threatening and had experienced uncomfortable treatments.

While all of the above post-treatment problems reported by women in the current study could be substantiated based on treatments received, the problems could also be related in unknown ways to memories of sexual trauma. Sexual trauma (e.g. sexual abuse, rape or domestic violence) tends to be a highly invisible event as well as the impact of it unless it is disclosed. Sexual trauma was rarely mentioned in cervical cancer literature, but it seemed quite reasonable that such trauma could be a factor for some women with cervical cancer (Basen-Engquist et al., 2003) or for women who are reluctant to participate in cervical cancer screening. The effects of such trauma might not only affect women's psychological adjustment prior to and following treatment, but how women view themselves, their relationships and perceptions of what others think of them. Even though the impact of sexual abuse with cervical cancer is unknown, one could easily make a conjecture concerning women's sexual self-concept and problems before and after cervical cancer treatment. Over 30% of women (n=21of 66) in the current study's sample reported past sexual trauma (e.g. sexual abuse or rape). The impact of the trauma was not determined. While nine percent of the women who had experienced sexual trauma also reported not being sexually active, it was not known if this was due to the trauma or post cancer problems.

Use and Strengths of the SHA Theory

The current study was well guided by the Sexual Health Adaptation (SHA) Theory, which was derived from Roy's Adaptation Model (2009). The major concepts of the theory included: stimuli (focal and contextual), coping processes (cognator and regulator) and output (adaptive and non-adaptive). The theoretical framework guided the identification of the specific focal stimuli (e.g. cancer treatment), contextual stimuli (e.g. time since treatment began, cervical cancer stage, age, race, health status, SES), coping processes (cognitive and religious coping) and the adaptive/non-adaptive outcome (sexual self-concept) and understanding its impact.

Promotion of health and adaptation in women after cervical cancer treatment was the outcome and goal of the study as it was prescribed by the SHA theory. The current study was the first to be led by the SHA Theory. The implication of the goal was advancement of sexual health assessment that could help provide a foundation for establishing interventions to more fully assist women after cervical cancer treatment.

Strengths

The research study was clinically relevant in response to the well-known persistent and stressful impact of cervical cancer treatment (Herzog & Wright, 2007) experienced by many women. Furthermore, the self-reported perceptions of the women's experiences contributed to the valuable quality of the study. The current study was conducted solely with women, who had cervical cancer and treatment. Much of the previous research grouped women, who had cervical cancer with other diverse gynecologic patients together in one sample. This usually limited interpretation of the impact of cervical cancer, treatment and any other pertinent assessments. Moreover,

the study included a racially diverse sample of women, community-based nationwide, of all ages, single, married, divorced, widowed, heterosexual, homosexual, sexually active and celibate. Much of the previous sexual self-concept research had been conducted with adolescents or young, White, college undergraduate females, who received college credit for their participation.

The study was strengthened by guidance provided from the middle-ranged Sexual Health Adaptation (SHA) theory derived from Roy's Adaptation Model. The current study was the first research study to be guided by the SHA theory. The theoretical consistency of selected variables and concepts with women's reported experiences strengthened the utility of the study outcomes and contributed to clinical significance. The research was an online study. Importantly, to project a sense of social distance in an effort to facilitate openness and ease of disclosure by the women, who had cervical cancer (Lyon, Cude, Lawrence & Gutter, 2005). Lastly, this study and theoretical framework could be instructive to future research related to sexual health adaptation of women and men.

Clinical Significance

The clearest findings that emerged from the results of the study were suggestions of potential implications for clinical significance, particularly with clinical practice and prognostic factors. The majority of the research hypotheses were partially supported; thus, the results might offer providers more information about which types of coping resources (religious versus cognitive) are needed by women at various times in treatment and with various stages of invasive cancer. Providers need to consider the opportunities to identify women at risk for sexual self-concept problems after cervical

cancer treatment. Since the variables included in the hypotheses were derived from a comprehensive theoretical framework, the clinical importance of a holistic view of sexual self-concept (esteem, satisfaction, sexual activity, sexual orientation) and coping (religious and cognitive) deserves a holistic clinical process, beginning with the sexual health assessment. Women used a variety of coping resources and reported a more expansive viewpoint of sexual self-concept, beyond sexual activity or intercourse.

In addition to the holistic view of sexual self-concept, providers might utilize the results to assist women with other health status challenges. Women in this study reported different associations between types of health status variables and types of coping. It may be that women need a variety of coping resources to adapt to problems such as cervical cancer post treatment. For example, negative religious coping was significantly correlated with the number of diseases while cognitive coping was correlated with health status, perception. The findings also revealed that time since treatment was negatively related to cognitive coping, which indicates that providers need to intervene early on post treatment. These findings also support the literature and the familiar adage, that “time and coping heals”, and thus, providers can offer this as hope to women, particularly women with invasive cancer.

Developing a sexual health assessment tool or questions that are easy, short and substantive to use in busy times and busy settings to identify women at risk and possibly indicate when help is or is not needed. Educating practitioners and providers in effective and sensitive communication related to sexual health, rape and sexual abuse education and shared decision making could be invaluable.

Limitations and Future Recommendations

The current study had several limitations. The response rate of possible participants was low and consequently sample size was small, though comparable to what seemed to be reflected in the cervical cancer literature. Since the study was correlational, causal relationships were not possible. Therefore, it is plausible that additional variables might explain relationships found, particularly since many concepts were multidimensional and difficult to define clearly. Use of the internet for this online study presented a few more challenges. The process of self-selection with the convenience sample could limit generalizability. There was no process/procedure to ensure that only one participant completed only one survey. A few online questionnaire design flaws contained in the demographic and health status form emerged during analyses that revealed small amounts of data either unusable or not thorough enough. As a doctoral student, program time and financial constraints negatively impacted participant recruitment and data collection timelines, likely contributing to the small sample size.

While limitations provide opportunities and inform future work, there are yet, a few more recommendations and policy suggestions that deserve mention. Future directions for cervical cancer and treatment research argue for a larger, random sample of diverse women, including Women of Color and women who have diverse sexual orientations. A diverse sample of women will help to understand the racial/ethnic, sexual orientation and social factors that impact on these results. An expanded sample could help predict a more suitable coping method or several worthy coping methods that might help women to more successfully adapt after cervical cancer and treatment.

Studies focused soley on women post cervical cancer treatment might uncover more valuable links between the important variables in this study. Previous research included women with diverse gynecologic cancers of different stages and treatments combined in the same studies. More research could be particularly salient with studies that utilizes a longitudinal design. Such a design could follow women from the start of treatment to several years post treatment to determine important variations in coping processes. A qualitative examination of these highly sensitive topics might also uncover information for women's sexual health. It could additionally obtain the important perspectives of women, who have experienced cervical cancer and the impact on their lives, including sexual functioning. Moreover, an analysis that included structural equation modeling might better clarify realtionships among variables using cross sectional data. For example, this could include exploring whether the significant negative correlation between time since treatment began and cognitive coping (focused and processing) implies successful adaptation or a diminished need. Examining coping at various points in time following treatment could provide pathways to helping women develop more and better ways of coping with cervical cancer treatment.

A critical policy implication is a need to change the current guidelines pertaining to the age cut off for the national screening for cervical cancer, the Breast and Cervical Cancer Program (BCCCP) and the guidelines by the United States Preventive Services Task Force and American College of Obstetricians and Gynecologists. Since older women, particularly women of color die more frequently from cervical cancer, a preventable and curable disease, reviewing and updating the current screening guidelines for a more realistic and older cutoff age for cervical cancer screening might

save lives if practiced. Given that close to 30% of the women in this study were 50 years or older and 12 % were over 60 years of age, leaving the decision to discontinue screening up to the provider may miss a significant opportunity to screen high risk women. This is relevant particularly with a health provider population that tend not ask about sexual behaviors in a comprehensive manner and with older women who are living a fuller life longer and not share the reality of their sexual lives. Another policy and/or technology implication is the need for a more accessible screening option for women at risk. A home test for HPV screening (similar to the home pregnancy test) might also save younger and older women's lives. Federal funds might be devoted for future prevention measures (i.e. home HPV testing) instead of the costly treatment options for late stage invasive treatment of women with cervical cancer.

APPENDIX A

WAYNE STATE UNIVERSITY

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87 East Canfield, Second Floor
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http://irb.wayne.edu

NOTICE OF EXPEDITED APPROVAL

To: Barbara Hollie
College of Nursing

From: Dr. Scott Millis
Chairperson, Behavioral Institutional Review Board (B3)

Date: March 01, 2012

RE: IRB #: 029912B3E

Protocol Title: Exploring Cervical Cancer Treatments, Coping-Adaptation and Women's Sexual Self-Concept after Cervical Cancer

Funding Source:

Protocol #: 1202010666

Expiration Date: February 28, 2013

Risk Level / Category: Research not involving greater than minimal risk

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The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review* Category (#7)* by the Chairperson/designee *for* the Wayne State University Institutional Review Board (B3) for the period of 03/01/2012 through 02/28/2013. This approval does not replace any departmental or other approvals that may be required.

- Protocol Summary Form (received in the IRB Office 02/28/2012)
- Protocol (received in the IRB Office 02/28/2012)
- Receipt of letter of support from Michigan Cancer Consortium (dated 02/16/2012)
- Receipt of letter of support from National Cervical Cancer Coalition (dated 02/16/2012)
- The request for a waiver of the requirement for written documentation of informed consent has been granted according to 45 CFR 46.117(1)(2). Justification for this request has been provided by the PI in the Protocol Summary Form. The waiver satisfies the following criteria: (i) the research involves no more than minimal risk to participants, (ii) the research involves no procedures for which written consent is normally required outside of the research context, (iii) the consent process is appropriate, and (iv) an information sheet disclosing the required and appropriate additional elements of consent disclosure will be provided to participants.
- Research Information Sheet (dated 02/20/2012)
- Study Advertisement
- Data collection tools: Research Questionnaire

- Federal regulations require that all research be reviewed at least annually. You *may* receive a *"Continuation Renewal Reminder"* approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval ***before*** the expiration date. Data collected during a period of lapsed approval is unapproved research and can never be reported or published as research data.
- All changes or amendments to the above-referenced protocol require review and approval by the IRB **BEFORE** implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (http://www.irb.wayne.edu//policies-human-research.php).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the IRB Administration Office must be contacted immediately.
2. Forms should be downloaded from the IRB website at **each** use.

APPENDIX B

CAPS (Focused and Balanced)

Directions: Sometimes people experience very difficult events or crises in their lives. Below is a list of ways in which people respond to those events. For each item please circle the number closest to how you personally respond: 1 = never; 2 = rarely; 3 = sometimes; 4 = always.

"When I experience a crisis or extremely difficult event, I…….. "

	Never	Rarely	Sometimes	Always
1. Generally come up with a new solution to a new problem	**1**	**2**	**3**	**4**
2. Gather as much information as possible to increase my options	**1**	**2**	**3**	**4**
3. Generally try to make everything work in my favor	**1**	**2**	**3**	**4**
4. Identify how I want the situation to turn out, then see how I can get there	**1**	**2**	**3**	**4**
5. Work hard to re-channel my feelings to a constructive approach	**1**	**2**	**3**	**4**
6. Keep my eyes and ears open for anything related to the event	**1**	**2**	**3**	**4**
7. Try to get more resources to deal with the situation	**1**	**2**	**3**	**4**
8. Try to be creative and come up with a new solution	**1**	**2**	**3**	**4**
9. Am likely to attack the crisis head on	**1**	**2**	**3**	**4**
10. Develop a plan with a series of actions to deal with the event	**1**	**2**	**3**	**4**

CAPS (Focused and Balanced)

	Never	Rarely	Sometimes	Always
11. Call the problem what it is and try to see the whole picture	**1**	**2**	**3**	**4**
12. Give myself time in the situation and do not act until I have full grasp of the situation.	**1**	**2**	**3**	**4**
13. Think through the problem systematically step by step	**1**	**2**	**3**	**4**
14. Put the event into perspective by seeing it for what it really is	**1**	**2**	**3**	**4**
15. Try to maintain balance in my activity and rest	**1**	**2**	**3**	**4**
16. Try clear up any uncertainties before I do anything else	**1**	**2**	**3**	**4**

APPENDIX C

Brief RCOPE

Below: make your answers as true FOR YOU as you can. Click on the answer that best applies to you.

1 – not at all 2 – somewhat 3 – quite a bit 4 – a great deal

I. Looked for a stronger connection with God.	1	2	3	4
2. Sought God's love and care.	1	2	3	4
3. Sought help from God in letting go of my anger.	1	2	3	4
4. Tried to put my plans into action together with God.	1	2	3	4
5. Tried to see how God might be trying to strengthen me in this situation.	1	2	3	4
6. Asked forgiveness for my sins.	1	2	3	4
7. Focused on religion to stop worrying about my problems.	1	2	3	4
8. Wondered whether God had abandoned me.	1	2	3	4
9. Felt punished by God for my lack of devotion.	1	2	3	4
10. Wondered what I did for God to punish me.	1	2	3	4
11. Questioned God's love for me.	1	2	3	4
12. Wondered whether my church had abandoned me.	1	2	3	4
13. Decided the devil made this happen.	1	2	3	4
14. Questioned the power of God.	1	2	3	4

APPENDIX D

MSSCQ

(Sexual Esteem and Sexual Satisfaction)

The items below refer to people's sexuality. Please read each item carefully and decide to what extent it is characteristic of you. Give each item a rating of how much it applies to you by clicking on one of the letters following each sentence based on how each letter is defined below.

A = Not at all characteristic of me
B = Slightly characteristic of me
C = Somewhat characteristic of me
D = moderately characteristic of me
E = Very characteristic of me

Note: Remember to respond to all items, even if you are not completely sure. Your answers will be kept in the strictest confidence. Also please be honest in responding to these statements.

I.

1. I derive a sense of self pride from the way I handle my own sexual needs and desires.

   A B C D E

2. I am proud of the way I deal with and handle my own sexual desires and needs.

   A B C D E

3. I am pleased with how I handle my own sexual tendencies and behaviors.

   A B C D E

4. I have positive feelings about the way I approach my own sexual needs and desires.

   A B C D E

5. I feel good about the way I express my own sexual needs and desires.

   A B C D E

MSSCQ

(Sexual Esteem and Sexual Satisfaction)

II.

1. I am satisfied with the way my sexual needs are currently being met.
   A B C D E
2. I am satisfied with the status of my own sexual fulfillment.
   A B C D E
3. The sexual aspects of my life are personally gratifying to me.
   A B C D E
4. The sexual aspects of my life are satisfactory, compared to most people's.
   A B C D E
5. I am satisfied with sexual aspects of my life.
   A B C D E

APPENDIX E

APPENDIX II 5

Socially Desirable Response Scale (SDRS-5)

Listed below are a few statements about your relationships with others. Select the response that identifies how much each statement is TRUE or FALSE for you.

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
1. I am always courteous even to people who are disagreeable.	1	2	3	4	5
2. There have been occasions when I took advantage of someone.	1	2	3	4	5
3. I sometimes try to get even rather than forgive and forget.	1	2	3	4	5
4. I sometimes feel resentful when I don't get my way.	1	2	3	4	5
5. No matter who I'm talking to, I'm always a good listener.	1	2	3	4	5

APPENDIX F

You are eligible:
If you are 18 years old or older, have had cervical cancer and one treatment or one series of treatments in the USA or you are currently in treatment and have been in treatment at least 3 months and have not had recurrent cervical cancer.

Please go to www.surveymonkey.com/s/CervicalCancerSurvey to complete the online questionnaire. Your participation will help improve the lives and health of women who have or will have cervical cancer.

If you have questions contact Barbara Hollie, ANP-BC
By phone, 313-690-4408 or email at aj8362@wayne.edu
College of Nursing, Wayne State University

APPENDIX G

Questionnaire

(Demographic Form and Measurement Tools Combined)

1. Where did you hear or learn about this research study? Choose all answers that apply.

- ☐ National Cervical Cancer Coalition
- ☐ Michigan Cancer Consortium member/organization
- ☐ Hospital
- ☐ Newsletter article
- ☐ Family member
- ☐ Friend/Acquaintance
- ☐ Doctor
- ☐ Nurse
- ☐ Flyer

Other (please specify)

2. What is your age range?

- ◯ 18 – 20
- ◯ 21 – 30
- ◯ 31 – 40
- ◯ 41 – 50
- ◯ 51 – 60
- ◯ 61 – 70
- ◯ 71 +

3. What is your race/ethnicity?

- ◯ African American/Black
- ◯ African
- ◯ Caucasian/White
- ◯ Arabic
- ◯ White Hispanic/Latino
- ◯ Non-White Hispanic/Latino
- ◯ Asian
- ◯ Hawaiian or Other Pacific Islander
- ◯ American Indian or Alaska Native
- ◯ Mixed race/ethnicity

Other (please specify)

4. What is your highest education level?

- ◯ Less than 8th Grade
- ◯ Less than 12th grade
- ◯ High School Graduate
- ◯ Completed Trade School
- ◯ Some College
- ◯ Associate Degree
- ◯ Bachelors Degree
- ◯ Masters Degree
- ◯ Doctorate

Other (please specify)

5. Which of the following best describes your total household income before taxes?

- ◯ Less than $20,000
- ◯ $20,000 - $40,000
- ◯ $40,000 - $60,000
- ◯ $60,000 - $80,000
- ◯ $80,000 - $100,000
- ◯ $100,000 - $300,000
- ◯ $300,000 - $500,000
- ◯ $500,000 or more

6. What religion do you practice?

- ◯ None
- ◯ Adventist
- ◯ Anglican/Episcopal
- ◯ Baptist
- ◯ Buddhist
- ◯ Catholic
- ◯ Congregationalist
- ◯ Hindu
- ◯ Islam
- ◯ Jehovah's Witness
- ◯ Jewish
- ◯ Lutheran
- ◯ Methodist
- ◯ Mormon
- ◯ Pentecostal/Apostolic
- ◯ Presbyterian
- ◯ Restorationist/Church of Christ/Disciples of Christ
- ◯ Unitarian

Other (please specify)

7. If you practice a religion, have you practiced since:

- ◯ Not applicable
- ◯ Childhood
- ◯ Young adulthood
- ◯ Middle-age
- ◯ Senior-age
- ◯ All my life
- ◯ Through childhood, but not since
- ◯ Childhood through young adulthood, but not since
- ◯ Childhood and Young adulthood through Middle-age, but not since

Other (please specify)

8. In general, choose the word(s) that best describes your health.

- ◯ Excellent
- ◯ Very Good
- ◯ Good
- ◯ Fair
- ◯ Poor

9. Do you have any of the following diseases? Choose all that apply.

- ☐ High Blood Pressure
- ☐ Heart Disease
- ☐ Diabetes
- ☐ Arthritis
- ☐ Kidney Failure
- ☐ Depression
- ☐ Anxiety
- ☐ I have no diseases

Other (please specify)

10. Do you take medications for: (Choose all that apply)

- ☐ High Blood Pressure
- ☐ Heart Disease
- ☐ Diabetes
- ☐ Arthritis
- ☐ Kidney Failure
- ☐ Depression
- ☐ Anxiety
- ☐ No prescribed medication taken

Other (please specify)

11. What stage is or was your cervical cancer?

- ○ Stage 0 (Pre-Cancer)
- ○ Stage I
- ○ Stage II
- ○ Stage III
- ○ Stage IV
- ○ Do not know

12. What kind of cancer treatment have you had for your cancer? Choose all that apply

- ☐ Laser Surgery
- ☐ Cone Biopsy
- ☐ Cryosurgery (Freezing Cells)
- ☐ Cauterization (Burning Cells)
- ☐ Other Surgery
- ☐ Chemotherapy
- ☐ Radiation Therapy

13. Write in when your treatment started. (Please use numbers, for example: Month: 2, Year: 2001.)

Month: ☐

Year: ☐

14. Write in when your treatment ended. (Please use numbers, for example: Month: 2, Year: 2001.)

Month: ☐

Year: ☐

15. If treatment not ended yet click here

◯ <- here.

16. Was your treatment received in the United States?

◯ Yes

◯ No

17. Relationship Status: Choose only one answer

◯ Single

◯ Single with same sex partner

◯ Single with opposite sex partner

◯ Widowed

◯ Married to opposite sex

◯ Married to same sex

◯ Separated

◯ Divorced

For the next 2 questions, please understand "sexually active" can include sexual behaviors or activities other than intercourse.

18. Are you presently sexually active in any way?

◯ No

◯ Yes

19. Have you ever been sexually active in any way?

- ◯ No
- ◯ Yes

20. If you had any of the following sexual health problems (or no problems) BEFORE your cancer was diagnosed and treated, Choose all answers that apply.

- ☐ Vaginal dryness
- ☐ Vaginal bleeding
- ☐ Vaginal tightness
- ☐ Low sex drive
- ☐ No sex drive
- ☐ Unable to climax
- ☐ Sexual dissatisfaction
- ☐ Had no problem(s)

Other (please specify)

21. If your cervical cancer treatment caused any of the following feelings (or did not). Choose all answers that apply.

- ☐ Pain
- ☐ Frightened
- ☐ Unattractive
- ☐ Guilty
- ☐ Low self worth
- ☐ Sad
- ☐ Angry
- ☐ Depressed
- ☐ Confused
- ☐ Tired
- ☐ Did not cause a change in feelings

Other (please specify)

22. If your cervical cancer treatment caused any of the following beliefs (or did not), Choose all answers that apply.

- ☐ I believe in myself more
- ☐ I believe in God more
- ☐ I believe in family and/or friends more
- ☐ I believe in myself less
- ☐ I believe in God less
- ☐ I believe in family and/or friends less
- ☐ I believe in medical health care more
- ☐ I believe in medical health care less
- ☐ No change in my beliefs

Other (please specify)

23. If you had any of the following sexual health problems (or no problems) AFTER your cervical cancer treatment, Choose all answers that apply

- ☐ Pain
- ☐ Vaginal dryness
- ☐ Vaginal Bleeding
- ☐ Vaginal tightness
- ☐ Low sex drive
- ☐ No sex drive
- ☐ Unable to climax
- ☐ Fear
- ☐ Sexual Dissatisfaction
- ☐ Had no problems

Other (please specify)

24. If you had any sexual health problems, who have you discussed the problem(s) with? Choose all answers that apply.

- ☐ Not applicable
- ☐ Husband/Partner
- ☐ Other Family Member
- ☐ Friend
- ☐ Doctor
- ☐ Nurse
- ☐ Counselor
- ☐ Religious Leader (example Minister/Rabbi/Imam/Priest)
- ☐ No One

Other (please specify)

25. Have you ever been hurt sexually by

- ☐ None
- ☐ Abuse
- ☐ Rape

Other Trauma (please specify)

Directions: Sometimes people experience very difficult events or crises in their lives. Below is a list of ways in which people respond to those events. For each item please click the choice closest to how you personally respond during crises:

"When I experience a crisis or extremely difficult situation, I…….. "

	Never	Rarely	Sometimes	Most of the time	Always
26. Generally come up with a new solution to a new problem	○	○	○	○	○
27. Gather as much information as possible to increase my options	○	○	○	○	○
28. Generally try to make everything work in my favor	○	○	○	○	○
29. Identify how I want the situation to turn out, then see how I can get there	○	○	○	○	○
30. Work hard to re-channel my feelings to a constructive approach	○	○	○	○	○
31. Keep my eyes and ears open for anything related to the event	○	○	○	○	○
32. Try to get more resources to deal with the situation	○	○	○	○	○
33. Try to be creative and come up with a new solution	○	○	○	○	○
34. Am likely to attack the crisis head on	○	○	○	○	○
35. Develop a plan with a series of actions to deal with the event	○	○	○	○	○
36. Call the problem what it is and try to see the whole picture	○	○	○	○	○
37. Give myself time in the situation and do not act until I have full grasp of the situation.	○	○	○	○	○
38. Think through the problem systematically step by step	○	○	○	○	○
39. Put the event into perspective by seeing it for what it really is	○	○	○	○	○
40. Try to maintain balance in my activity and rest	○	○	○	○	○
41. Try and clear up any uncertainties before I do anything else	○	○	○	○	○

Directions: Below make your answers as true FOR YOU as you can, related to when you were diagnosed and treated for cervical cancer or if you are in treatment now for cervical cancer. Click on the answer that best applied to you.

	Not at all	Somewhat	Quite a bit	A great deal
42. Looked for stronger connection with God.	○	○	○	○
43. Sought God's love and care.	○	○	○	○
44. Sought help from God in letting go of my anger.	○	○	○	○
45. Tried to put my plans into action together with God.	○	○	○	○
46. Tried to see how God might be trying to strengthen me in this situation.	○	○	○	○
47. Asked forgiveness for my sins.	○	○	○	○
48. Focused on religion to stop worrying about my problems	○	○	○	○
49. Wondered whether God had abandoned me.	○	○	○	○
50. Felt punished by God for my lack of devotion.	○	○	○	○
51. Wondered what I did for God to punish me.	○	○	○	○
52. Questioned God's love for me.	○	○	○	○
53. Wondered whether my church had abandoned me.	○	○	○	○
54. Decided the devil made this happen.	○	○	○	○
55. Questioned the power of God.	○	○	○	○

The items below refer to people's sexuality. Please read each item carefully and decide to what extent it is characteristic of you at this time. Give each item a rating of how much it applies to you now by clicking on one of the choices following each sentence.

Note: Remember to respond to all items, even if you are not completely sure. Your answers will be kept in the strictest confidence. Also please be honest in responding to these statements.

	Not at all characteristic of me	Slightly characteristic of me	Somewhat characteristic of me	Moderately characteristic of me	Very characteristic of me
56. I derive a sense of pride from the way I handle my own sexual needs and desires.	◯	◯	◯	◯	◯
57. I am proud of the way I deal with and handle my own sexual desires and needs.	◯	◯	◯	◯	◯
58. I am pleased with how I handle my own sexual tendencies and behaviors.	◯	◯	◯	◯	◯
59. I have positive feelings about the way I approach my own sexual needs and desires.	◯	◯	◯	◯	◯
60. I feel good about the way I express my own sexual needs and desires.	◯	◯	◯	◯	◯
61. I am satisfied with the way my sexual needs are currently being met.	◯	◯	◯	◯	◯
62. I am satisfied with the status of my own sexual fulfillment.	◯	◯	◯	◯	◯
63. The sexual aspects of my life are personally gratifying to me.	◯	◯	◯	◯	◯
64. The sexual aspects of my life are satisfactory, compared to most people's.	◯	◯	◯	◯	◯
65. I am satisfied with sexual aspects of my life.	◯	◯	◯	◯	◯

Listed below are a few statements about your relationships with others. Select the response that identifies how much each statement is TRUE or FALSE for you at this time.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
66. I am always courteous even to people who are disagreeable	◯	◯	◯	◯	◯
67. There have been occasions when I took advantage of someone	◯	◯	◯	◯	◯
68. I sometimes try to get even rather than forgive and forget	◯	◯	◯	◯	◯
69. I sometimes feel resentful when I don't get my way	◯	◯	◯	◯	◯
70. No matter who I'm talking to, I'm always a good listener	◯	◯	◯	◯	◯

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ABSTRACT

EXPLORING CERVICAL CANCER TREATMENTS, COPING ADAPTATION AND WOMEN'S SEXUAL SELF-CONCEPT AFTER CERVICAL CANCER

by

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Cervical cancer survivorship is increasing as a result of improved biomedical science and health care. Due to the nature of cervical cancer treatments most cures are not without consequences. Despite the progress in cancer treatments, associated side-effects persist and it is well established that sexual problems result from most of the available treatment options. Subsequently, cervical cancer treatment alters how women cope and experience their sexual self-concept after treatment. Poor coping and a non-adaptive sexual self-concept following cervical cancer treatment can result in low sexual satisfaction and low sexual esteem for women. This study, entitled "Exploring Cervical Cancer Treatments, Coping Adaptation, and Women's Sexual Self-Concept after Cervical Cancer" examined associations among cancer treatment, select demographic variables, coping and sexual self–concept; identified possible predictor variables for an adaptive sexual self-concept and explored the mediating influence of coping. Participants completed an online survey and a descriptive correlation design was used with bivariate correlation, linear and exploratory multiple regression and mediation analysis. This study explored variables to help identify women at risk for

sexual self-concept problems prior to treatment and understand the impact of coping and cervical cancer treatment(s) on sexual self-concept.

AUTOBIOGRAHICAL STATEMENT

My educational and professional background includes an Associate Degree in Nursing from Schoolcraft College, Livonia, Michigan; Bachelors of Science in Nursing and a Masters of Science in Nursing from Wayne State University, Detroit, Michigan. I am a Board Certified Adult Nurse Practitioner with a major focus in primary care. My professional career has included working as a staff nurse, nurse manager, nursing supervisor and clinical nurse specialist in acute care. I have worked as a gerontological nurse practitioner and gyn-oncology nurse practitioner. For three years during my doctoral program I worked as an adjunct clinical instructor at Madonna University and for two years following my work as a clinical instructor, I worked as an assistant professor at Madonna University College of Nursing in Livonia, Michigan. My goal is to continue to teach nursing students, work with women who have experienced cervical cancer treatment and help develop and test interventions that will help women adapt successfully after cervical cancer treatment.