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Relationship of Illness Perception and Fear of Cancer Recurrence to Psychological Distress among Gynecologic Cancer Survivors

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Relationship of Illness Perception and Fear of Cancer Recurrence to Psychological Distress among Gynecologic Cancer Survivors

by

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Dedication

This dissertation is dedicated to all of the gynecologic cancer survivors who participated in the study, and to my mother who is not with me anymore, but who always encouraged me to study more and more. Without the support of my family and friends, this work would never have been started or finished.

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Relationship of Illness Perception and Fear of Cancer Recurrence to Psychological Distress among Gynecologic Cancer Survivors

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Gynecologic cancer survivors account for approximately 9% of all cancer survivors, and about 40% of the gynecologic cancer survivors have been reported to experience some form of psychological distress. Further, fear of cancer recurrence is prevalent among gynecologic cancer survivors, and illness perceptions influence psychological distress among cancer patients in general. Although a growing body of research has begun to document problems that cancer survivors experience, the generalizability of these findings related to psychological distress among gynecological cancer survivors is unclear.

The overall purpose of this exploratory, descriptive study was to explore the relationship between psychological distress, illness perception, and fear of cancer recurrence among gynecologic cancer survivors. The central theme of this study was that

gynecologic cancer survivors' illness perception and fear of cancer recurrence in combination with select demographic variables could predict survivors' psychological distress.

Findings from this study suggested that higher levels of psychological distress, fear of cancer recurrence, and illness perceptions were seen among younger aged and early survivors. Additionally, psychological distress, fear of cancer recurrence, and illness perception were slightly lower for non-Whites than Whites. A negative correlation was noted between psychological distress, fear of cancer recurrence, and illness perception with age and survivorship duration among both Whites and non-Whites. Finally, the results suggested that illness perception and survivorship duration were the best predictor variables for psychological distress among White participants; however, for non-White participants, illness perception alone was found to be the best predictor for psychological distress.

The overarching conclusion was that gynecologic cancer survivors experienced psychological distress, and that fear of cancer recurrence and illness perception played a role in the psychological distress experienced by survivors. These findings were closely aligned with other studies' conceptualizations of survivors with other forms of cancer. Further, results indicated that non-Whites may experience psychological distress differently from Whites. However, this finding should be viewed with caution because of the small number of non-White participants in this study. It may also be concluded that younger survivors and those with shorter duration from treatment completion have more psychological distress, fear of cancer recurrence, and illness perception.

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Chapter 1: Introduction to the Study

INTRODUCTION

Cancer remains a major public health problem with an estimated 10.5 million Americans living with a history of cancer. It is projected that this number will double by the year 2030 (Edwards et al., 2002). Although the number of new cancer diagnoses increased between 1971 and 2010, the corresponding mortality rate has declined (American Cancer Society (ACS), 2012). Furthermore, it is believed that approximately 68% of adults diagnosed with cancer will be alive after five years from their diagnosis (Siegel et al., 2012). It is estimated that by 2022 the population of cancer survivors will increase to almost 18 million: 8.8 million males and 9.2 million females (ACS, 2012). Breast cancer survivors are the largest group of cancer survivors (22%), followed by prostate cancer survivors (17%) and colorectal cancer survivors (11%) (Valdivieso et al., 2012). Gynecologic cancer survivors account for approximately 9% of all cancer survivors (Urbaniec et al., 2011).

Studies have shown that individuals living beyond cancer and entering into the survivorship phase have different health and emotional needs than patients in diagnosis and acute treatment phases (Khan et al., 2012). Most research conducted on quality of life during cancer survivorship has focused on short- and long-term biomedical outcomes such as fatigue, pain, sleep disorders, neurocognitive changes, and symptom burden (Burkett & Cleeland, 2007). These factors are known to introduce additional stress, going as far as to prevent cancer survivors from participating in activities that give purpose and meaning to their lives (Mah et al., 2011). It is known that cancer survivors may continue

to experience several problems, including health issues, psychological distress, and disruption of social life, decades after diagnosis and treatment completion (Bloom, 2002). For many survivors, stressors associated with cancer persist long after treatment completion, even when survival is virtually assured (Diemling, 2006). Therefore, it is important to address the psychological aspects of cancer survivorship because it is a vulnerable point in the cancer care continuum. For the purpose of this study, cancer survivors are defined as those who have completed cancer treatment at least 2 years prior to data collection and have remained disease-free since completion of cancer treatment. Those who are disease-free 2-5 years following treatment completion are considered to be "early survivors," and those who are disease- free for over 5 years are considered to be "long-term survivors". In this study, cancer survivorship was measured using: 1) survivorship status (early survivors versus long-term survivors); and 2) survivorship duration (number of disease-free years).

PROBLEM STATEMENT

Cancer survivorship is viewed as a process that continues across one's lifespan (Bowman, 2003), and cancer survivors may experience many problems including psychological distress and disruption of social life several decades after diagnosis and treatment (Bloom, 2002). Gynecologic cancer survivors account for approximately 9% of all cancer survivors (Urbaniec et al., 2011). Among this group, approximately 40% are reported to have experienced psychological distress, 28.9% experienced clinical anxiety (Urbaniec et al., 2011), 20.0% experienced mild-to-severe depression, and 15.6% are reported to have undergone probable posttraumatic stress disorder (Urbaniec et al., 2011).

Furthermore, fear of cancer recurrence is a prevalent problem among gynecologic cancer survivors (Goncalves, 2010), and a higher fear of recurrence is correlated with syndromes such as post-traumatic stress disorder in long-term survivors (Mehnert et al., 2009). In addition, illness perceptions have been shown to explain a significant proportion of psychological distress among cancer patients (Millar et al., 2005; Scharloo et al., 2005). To develop effective interventions to address psychological distress among gynecologic cancer survivors, it is important to understand how the constructs of fear of cancer recurrence and illness perceptions are related to psychological distress. Although a growing body of research has begun to document problems experienced by cancer survivors, the generalizability of these findings related to psychological distress among gynecologic cancer survivors is unclear. Lack of such knowledge poses a significant problem because it impedes our ability to understand psychological distress among survivors of gynecologic cancer.

PURPOSE STATEMENT

The purpose of this study was to explore the relationship between psychological distress, illness perception, and fear of cancer recurrence among gynecologic cancer survivors. The long-term goal of this study was to develop interventions to help women who suffer from psychological distress and produce subsequent improvements in quality of life among gynecologic cancer survivors.

CENTRAL THEME

The central theme of this study was that gynecologic cancer survivors' illness perception and fear of cancer recurrence in combination with select demographic variables could predict their psychological distress. The rationale for conducting this research stemmed from the possibility that the relatedness of illness perception, fear of cancer recurrence, and psychological distress could provide a foundation for the development of interventions that would assist in addressing psychological distress among gynecologic cancer survivors.

SPECIFIC AIMS AND RESEARCH QUESTIONS

The following specific aims and research questions were addressed in this study.

Specific Aim 1

Explore the characteristics of psychological distress, illness perception, and fear of cancer recurrence across age groups, survivorship status (early survivors, 2-5 years vs. long-term survivors, >5 years), and racial/ethnic groups (White versus non-White).

RESEARCH QUESTION 1.1

What are the distribution characteristics of psychological distress, illness perception, and fear of cancer recurrence across age groups, survivorship status (early survivors, 2-5 years vs. long-term survivors, >5 years), and racial/ethnic groups (White versus non- White)?

Specific Aim 2

Explore the relationships between psychological distress, illness perception, and fear of cancer recurrence with age and survivorship duration (number of disease-free years) within racial/ethnic groups.

RESEARCH QUESTION 2.1

What is the relationship between psychological distress, fear of cancer recurrence, and illness perception with age and survivorship duration (number of disease-free years) within racial/ethnic groups (White versus non- White)?

RESEARCH QUESTION 2.2

What are the differences in psychological distress, illness perception and fear of cancer recurrence across age groups, survivorship status (early survivors, 2-5 years vs. long-term survivors, >5 years) and racial/ethnic groups (White versus non-White)?

RESEARCH QUESTION 2.3

Do illness perception, fear of cancer recurrence, age, and survivorship duration predict psychological distress across race/ethnicity among gynecologic cancer survivors?

SIGNIFICANCE OF THE STUDY

Individuals are considered survivors from the time of diagnosis through the remainder of their lives, and quality of life is viewed as a key outcome of survivorship (Siegel et al., 2012). Psychological well-being has been described as the most important contributor to overall quality of life in cancer survivors (Bloom, 2002; Dempster et al.,

2012; Ferrell et al., 2003). Because cancer survivors are growing in number, the Institute of Medicine (IOM) has urged health care providers to address the psychological needs of cancer patients, both through the effective detection of distress and the provision of appropriate support services. Gynecologic cancer survivors account for approximately 9% of all cancer survivors. Approximately 40% of gynecologic cancer survivors have reported experiencing some form of psychological distress (Goncalves, 2010).

Relatedly, illness perceptions (IP) are known to cause different levels of psychological distress (PD) among cancer patients (Millar et al., 2005; Scharloo et al., 2005), and relationships between IP and PD vary among different types of cancer (Dempster et al., 2012). It has been shown that IP, a component of psychological well-being, can be influenced by individuals' emotional state, which in turn can be influenced by individuals' IP (Dempster et al., 2011). However, it remains unclear how IP affects gynecologic cancer survivors' psychological well-being.

Additionally, fear of cancer recurrence (FCR) is a known problem among a majority of cancer survivors (Bloom et al., 2004), and higher FCRs have been correlated with post-traumatic stress disorder in cancer survivors (Mehnert et al., 2009). Furthermore, FCR is prevalent (56%) among gynecologic cancer survivors (Goncalves, 2010), diminishing their quality of life and overall sense of well-being (Cimprich, 2002). A study among long-term (>5 years) early-stage ovarian cancer survivors revealed a significant amount of distress related to FCR (22%) and fears of a second cancer (36%) (Wenzel, 2002).

It is evident that cancer survivors may continue to experience PD decades after diagnosis and treatment (Bloom, 2002). For many survivors, cancer associated stressors persist long after treatment has ended (Diemling, 2006). Studies have shown that PD is prevalent among gynecologic cancer survivors (Goncalves, 2010), while IP and FCR have been associated with PD (Hong, 2010; Millar et al., 2005; Scharloo et al., 2005). However, there is limited research to explain how these variables are related in gynecologic cancer survivors.

This study is important because, once detected, treatment of cancer-related distress among gynecologic cancer survivors could mitigate the costly economic impact of untreated PDs (Carlson & Bultz, 2003). In addition, as increasing numbers of advanced practice nurses (APN) participate in the care of cancer patients and survivors, a better understanding of PD and related variables among gynecological cancer survivors may assist with early detection of PD and provision of appropriate support services.

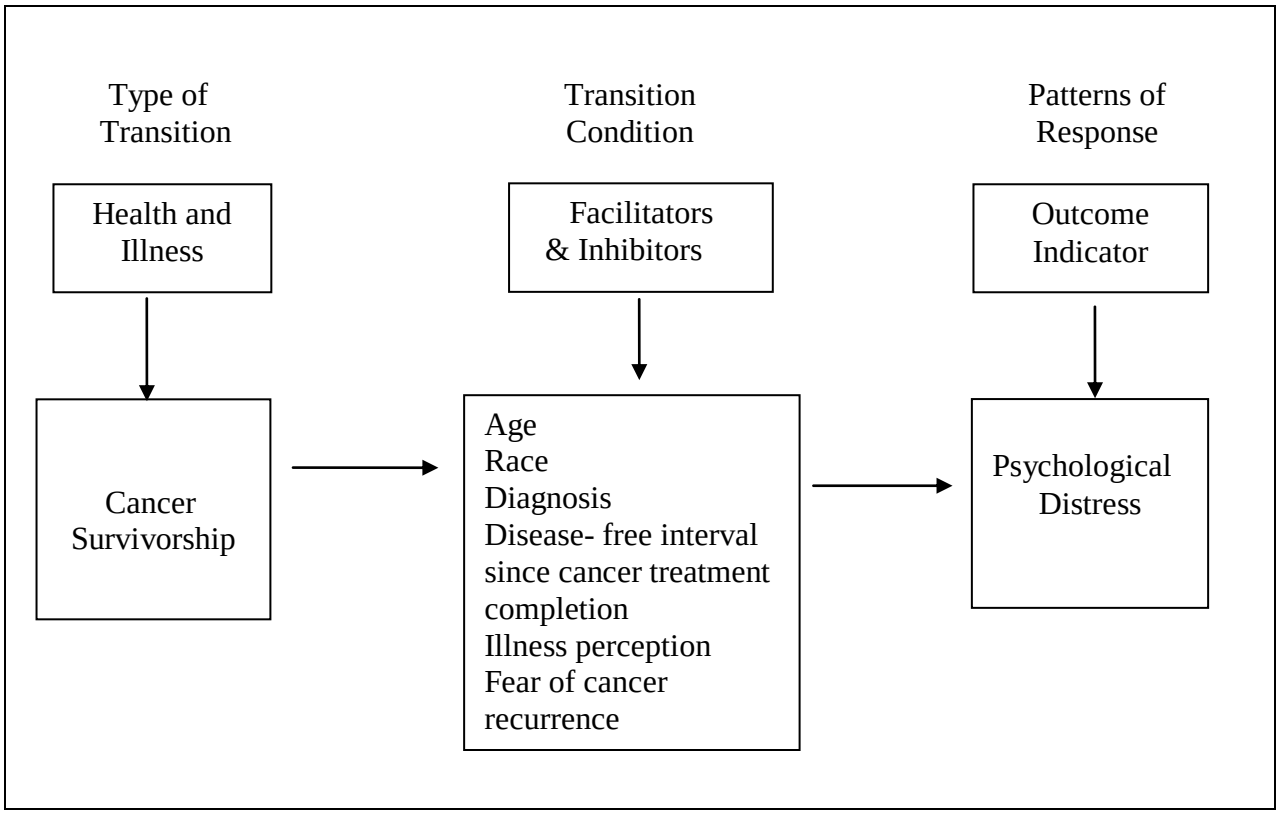
CONCEPTUAL FRAMEWORK

This study explored the relationship between PD, IP, and FCR and select demographic variables among gynecological cancer survivors through comparisons of early survivors and long-term survivors. Survivorship is a transition from active treatment for cancer, and it is a vulnerable point in the cancer care continuum that can affect survivors' well-being. Meleis et al.'s (2000) Transition theory was used to understand whether women's IP and FCR directly influenced their PD during the survivorship phase. Chick and Meleis (1986) defined transition as a passage or movement from one state, condition, or place to another.

Major concepts of this middle range theory of transition include the following: (a) types of transitions; (b) properties of transition experiences; (c) transition conditions (facilitators and inhibitors); (d) process indicators; (e) patterns of response (outcome indicators or response); and (f) nursing therapeutics. For the purpose of this study, three concepts from this framework were used: 1) type of transition, 2) transition conditions, and 3) patterns of response. Other concepts were outside the scope of this study. Four types of transitions were included in the Transition theory: developmental, health and illness, situational, and organizational transition.

In the current study, participants were gynecological cancer survivors, and cancer survivorship was considered to be a health and illness type of transition. Transition conditions are circumstances that influence the way a person transitions through and facilitates or hinders progress toward achieving a healthy transition (Schumacher & Meleis, 1994). Transition conditions may include personal, community, or societal factors that may facilitate or constrain the processes and outcomes of healthy transitions. For this study, the transition conditions included demographic factors, diagnosis, disease-free interval since treatment completion, IP, and FCR (see Figure 1). Patterns of response were conceptualized as outcome indicators or response. PD was the outcome indicator in this study.

Figure 1: Model of Cancer Survivorship Transition Using Study Variables



Adapted from Transition Theory (Meleis, 2000)

BRIEF OVERVIEW OF DESIGN

An exploratory, cross-sectional descriptive research design was used for this study. Data collection was performed through a web-based survey administered to a convenience sample of gynecologic cancer survivors. Descriptive statistics, Pearson correlation coefficient, t-test, Mann-Whiney U, stepwise forward, and backward multiple regression were used to analyze the data.

DELIMITATIONS

1. The timeline of this study was from March 2013 to May 2013.
2. The study setting was the Internet.
3. Women with a history of uterine/endometrial, ovarian, and cervical cancers that had been disease free for at least 2 years since treatment completion, who could read and write English, and who were 21 years or older were included in this study.

ASSUMPTIONS

1. The sample studied was representative of the gynecologic cancer survivors.
2. The self-report responses received from the participants by completing the web-based survey best reflected their experience of PD, FCR, and IP.

DEFINITION OF RELEVANT TERMS

For the purposes of this study, the following terms were conceptually and operationally defined:

1. *Illness Perception (IP):* IP was defined as the beliefs held by patients about their health problems (Cavelti et al., 2012). This variable was operationalized by Broadbent et al.'s (2006) Brief Illness Perception Questionnaire (BIPQ).
2. *Fear of Cancer Recurrence (FCR*): FCR was defined as the experience of worry and concern that cancer might return to the same organ or spread to another part of the body (Vickberg, 2003). This variable was operationalized by Kornblith's (1998) Fear of Recurrence Scale (FOR).
3. *Psychological Distress (PD):* PD accurately describes individualized patient responses to illness (Ridner, 2004). PD is generally referred to a general concept of "maladaptive psychological functioning in the face of stressful life events" (Abeloff et al., 2000). For this study, this variable was operationalized by Horowitz et al.'s (1979) Impact of Events Scale (IES).
4. *Survivorship*: This study defined survivors as individuals who have completed cancer treatment at least 2 years prior to data collection and have remained disease-free since treatment completion. Those who had been disease-free for 2-5 years from cancer treatment completion were considered to be early survivors, and those who had been disease-free for over 5 years were considered to be long-term survivors (Bloom et al., 2007; Grov et al., 2011; Wenzel, 2002). For this study, survivorship was measured using 1) survivorship status (early survivors versus long-term survivors), and 2) survivorship duration (number of disease-free years).

ORGANIZATION OF THE STUDY

The dissertation is divided into five chapters. Chapter one represents the introduction, problem statement, purpose, objective of the study, specific aims, research questions, significance of the study, conceptual framework, and definition of relevant terms. Chapter two presents a review of literature, including an overview of cancer survivorship and in-depth review of each variable in the context of cancer survivorship. Chapter three presents an overview of the objective of the study, research design, sample, setting of the study, data collection procedure, analyses used to address research questions, and instruments. Chapter four presents the results from the data analysis. Chapter five presents the findings, conclusions, implications for nursing, and recommendations for future research.

Chapter 2: Review of Literature

INTRODUCTION

This chapter presents a description of cancer survivorship, definition of cancer survivor, challenges of cancer survivors, relevant literature on psychological distress, fear of cancer recurrence, and illness perception. In addition, this chapter will identify the gaps in the literature, rationale for the study, and address how this study will address the gap.

CANCER SURVIVORSHIP

It is estimated that in 2012 there were approximately 13.7 million cancer survivors in the United States, representing approximately 4% of the population. Due to advances in medicine, early cancer detection and effective treatments, the number of individuals living beyond cancer diagnosis is expected to increase further (Aziz, 2007; Hoffman et al., 2009; Meyerowitz et al., 2008; Philips, 2012). By the year 2022, population of cancer survivors is projected to increase to almost 18 million: 8.8 million males and 9.2 million females (American Cancer Society, 2012). Of all cancer survivors, breast cancer survivors have comprised the largest group of cancer survivors, followed by prostate cancer survivors and colorectal cancer survivors (Valdivieso et al., 2012).

Gynecologic cancer survivors have accounted for approximately 9% of all cancer survivors (Urbaniec et al., 2011). Among gynecologic cancers, ovarian cancer has been determined to be the fourth leading cause of cancer-related deaths in women (ACS, 2006). Medical advances have resulted in more women treated for ovarian cancer

surviving longer than 5 years and women younger than 65 being twice more likely to survive five years after diagnosis than who are 65 years or older (ACS, 2006). Among women with ovarian cancer, approximately 19% were diagnosed at an early stage of disease and had the highest survival rate (94%) (ACS, 2006). Although cervical cancer has remained a problem, survival rate was significantly associated with stage of the disease. It was reported that the overall 5-year relative survival for cervical cancer from 2003-2009 was 67.9%, and 5-year relative survival was 69.1% for White women and 59.2% for Black women (Howlader et al., 2012). As the number of survivors' increases, a better understanding of the psychological effects related to the disease and treatments is needed to provide optimal and comprehensive care (Meyerowitz et al., 2008).

DEFINITION OF CANCER SURVIVORSHIP

Despite widespread use of this term, the operational definition of "cancer survivor" has been inconsistent. The concept of "survivorship" was first developed as a stage of survival by Fitzhugh Mullan, an American physician who was diagnosed with cancer in the 1980s (Khan et al., 2012; Hodgkinson et al., 2007). Mullan (1985) defined survivorship as an independent phenomenon with unique challenges and definable seasons or phases faced by cancer survivors. The *acute survival* phase is the period of early diagnostic and treatment phase (usually occurring in the first year); *extended survival* falls into the early survivorship period when the active treatment has been completed (one to three years time period) (Mullan, 1985). *Permanent survival* is the phase in which individuals enter into a long-term adjustment where a "normal" life is re-established and individuals re-adjust to life as those who have survived cancer (Mullan,

1985). However, medical communities usually define cancer survivors as individuals who have been disease-free for 5 or more years (Hodgkinson et al., 2007). Other groups consider "survival" as a process in which patients may exist at any point from diagnosis, including ongoing disease or remission (Hogkinson, 2007).

As a result of strong advocacy efforts led by organizations such as the National Coalition for Cancer Survivorship (NCCS), the term "cancer survivor" has been redefined. These groups define "cancer survivors" as individuals who have been diagnosed with cancer, with the survivorship period extending from the time of diagnosis through the balance of one's life (Siegel et al., 2012). The National Cancer Institute (NCI) then expanded the definition of cancer survivor to include caregivers and family members; this expanded the definition to include people diagnosed with cancer, their family members, friends and caregivers (Aziz, 2002). Other researchers use end of active treatment as an arbitrary cutoff or a cutoff of 5 years post-diagnosis to define and target survivorship research (Khan et al., 2012).

The current study defined "cancer survivors" as those who have completed treatment at least 2 years prior to data collection and remained disease-free since completion of cancer treatment. Those individuals who were disease-free for 2-5 years from cancer treatment completion were considered early survivors, and those who were disease-free for over 5 years were considered long-term survivors; this definition was supported by a previous study (Grov et al., 2011). In summary, survivorship was measured in this study using 1) survivorship status (early survivors versus long-term survivors), and 2) survivorship duration (number of disease-free years).

CHALLENGES OF CANCER SURVIVORS

Cancer survivorship is considered to be a vulnerable point in the cancer care continuum (Janz, 2011) and viewed as a process that continues across the lifespan (Bowman, 2003). The diagnosis, treatment, and long-term management of cancer can present individuals with a multitude of stressors that may include physical symptoms, emotional distress, difficulty maintaining interpersonal relationships, and financial strains (Philips, 2012). Cancer survivors may continue to experience health problems including psychological distress decades after diagnosis and treatment completion (Bloom, 2002). It has been found that the stressors associated with cancer can persist long after treatment has ended (Diemling, 2006). Some believe that individuals living past cancer and surviving into the long-term phase may experience different health and emotional needs than those patients in the diagnosis and acute treatment phases (Khan et al., 2012). Most research on cancer survivors' quality of life largely has focused on biomedical outcomes such as fatigue, pain, sleep disorders, neuro-cognitive changes, and symptom burden (Burkett & Cleeland, 2007) and these factors have been shown to introduce additional stress to survivors (Philips, 2012).

When considering the psychological health of cancer survivors, most of the research literature has emphasized the potential for depression and anxiety. While depression and anxiety are known negative psychological responses in cancer survivors, other responses and reasons for psychological distress need to be addressed. Among the many causes, illness perceptions (IP) have been demonstrated to cause different levels of psychological distress (PD) among cancer patients (Millar et al., 2005; Scharloo et al.,

2005), and the nature of relationship between IP and PD vary among different types of cancer (Dempster et al., 2012). Similarly, FCR is another known problem for a majority of survivors (Bloom et al., 2004) and higher FCRs are correlated with post-traumatic stress disorder among cancer survivors (Mehnert et al., 2009). Studies have shown that about one-third of cancer patients experiences distress and thus could benefit from early psychosocial intervention (Zabora et al., 2001); however, only about 10% of these individuals receive any psychosocial therapy (Holland & Alici, 2010).

Gynecologic cancers have accounted for approximately 18% of all female cancers worldwide (Ferlay et al., 2004). The most common gynecologic cancers are endometrial, ovarian and cervical cancer (Goncalves, 210). Advancements in treatments have improved overall cancer survival rates, resulting in gynecologic cancer survivors that account for approximately 9% of all cancer survivors (Goncalves, 2010). Like other cancer survivors, gynecologic cancer survivors experience PD (Goncalves, 2010). Yet limited evidence exists to explain how IP, FCR, and PD are related to each other in gynecologic cancer survivors.

PSYCHOLOGICAL DISTRESS

PD has been widely used as an indicator of mental health (Drapeau, 2012) and has been largely defined as a state of emotional suffering characterized by symptoms of depression and anxiety (Mirowsky & Ross 2002). PD has been viewed as an emotional disturbance that may impact the social functioning and day-to-day living of individuals (Wheaton, 2007). Some researchers have suggested that PD vanishes when stressors disappear or when individuals effectively cope with stressors (Ridner, 2004). Tenets of

the stress-distress model are that PD is exposure to a stressful event that threatens physical or mental health, leads to an inability to cope effectively with the stressor, and creates emotional turmoil that results from ineffective coping (Horwitz, 2007; Ridner, 2004).

Ridner (2004) further defined PD as a unique, discomforting, emotional state experienced by individuals in response to a specific stressor, which may result in either temporary or permanent harm. Ridner (2004) also indicated that the term "psychological distress" may better describe individualized patient responses to illness in which nurses intervene. Oncology nursing literature's definition for PD is a general concept of maladaptive psychological functioning in the face of stressful life events (Abeloff et al., 2000). In the current study, PD has been conceptualized as individualized patient responses to illness (cancer), and measured by the Impact of Events Scale (IES) which is a self-report measure designed to assess subjective distress for any specific life event (Horowitz et al., 1979).

In many studies, psychological well-being has been considered the most important contributor to cancer survivors' overall quality of life (Bloom, 2002; Dempster et al., 2012; Ferrell et al., 2003). In 2003, the National Comprehensive Cancer Network (NCCN, 2009) addressed the stigma attached to "psychological problems" by choosing to use the word "distress" because it is more readily accepted and less embarrassing than psychological or psychiatric terminology. In the context of cancer, NCCN defined "distress" as being "a multi-factorial unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with

cancer, its physical symptoms, and its treatment" (Holland, 1999). Psychological sequelae associated with cancer diagnosis and treatments include fear, stress, depression, anger, and anxiety (Diemling, 2006). Additionally, survivors may live with the uncertainty and fear that cancer might return (Diemling, 2006; NCI, 2002). Further, some evidence has suggested that relationships may exist between PD and cancer progression (Antoni et al., 2006) as well as PD and reduced overall survival (Groenvold et al., 2007).

Studies have shown that PD is prevalent among cancer survivors (Bloom, 2002; Goncalves, 2010) and that IP and FCR have been found to be associated with PD (Hong, 2010; Millar et al., 2005; Scharloo et al., 2005). Lazarus & Folkman (1984) identified distress caused by illness as one of the most prevalent problems faced by individuals and one which professionals frequently fail to acknowledge. Although most cancer survivors adapt to their lives after cancer treatment, it has been now recognized that some survivors may develop long-lasting, significant psychological sequelae. Studies suggest that even for survivors who report excellent emotional adjustment and low levels of distress, there are almost always areas of continuing disruption and difficulties during the survivorship phase (Meyerowitz et al., 2008).

The prevalence of psychiatric disorders in cancer patients is approximately 50% (NCCN, 2009), and the prevalence of PD varies with disease site and prognosis (Holland & Alici, 2010). A needs assessment survey done in ambulatory clinics using a distress thermometer revealed that 20%-40% of cancer patients reported significant levels of distress (NCCN, 2009). In another study using a sample of 14 different cancer diagnoses (N = 4,496), the overall incidence of PD was 35.1%. The rate varied with diagnosis, from

43.4% for lung cancer to 29.6% for gynecological cancers (Zabora et al., 2001). Increase in overall survival rates in cancer patients has led to several distressing symptoms, such as fatigue, pain, anxiety, depression and cognitive impairment, which may interfere with people's ability to perform daily activities (Zabora et al., 2001). Early identification of distress could facilitate effective management of PD; however, studies of psychiatric consultation data revealed that treatable psychiatric problems continue to be under-diagnosed and undertreated, despite their high prevalence in cancer patients (NCCN, 2009).

There is an ongoing debate on the prevalence of psychological effects during the survivorship phase. Most investigations have concluded that emotional quality of life and psychosocial adjustment are good for the majority of disease-free, long-term cancer survivors (Bloom et al., 2007). Some experts have claimed that for a majority of survivors, the emotional and psychosocial aspects improve during the first two years after treatment and stabilize thereafter (Burgess et al., 2005). However, other researchers believe that by 5 years after diagnosis, psychosocial levels are comparable with or better than those of individuals who have not had cancer (Ganz et al., 2002).

To date, most of the research into the psychological impact of cancer survivorship among women has focused on breast cancer, although approximately 9% of all cancer survivors have been women who survived gynecologic cancers. Therefore, a need to evaluate the psychological effects of survivorship among this group was present. Goncalves's (2010) literature review on the long-term quality of life among gynecologic cancer survivors found that about 40% of the survivors experienced PD. Subsequently,

Urbaniec et al. (2011) evaluated PD and unmet supportive care needs among gynecologic cancer survivors. This study used a cross sectional design in which participants were identified from the Gynecologic Oncology Clinics and database at the Royal Adelaide Hospital Cancer Center in South Australia. Eligible participants had been diagnosed at least one year prior to study commencement and had completed primary treatment. Of the 75 survivors who met the eligibility criteria, 45 were included in the final sample. The results revealed that 28.9% of participants reported clinical anxiety, 20.0% had mild-to-severe depression, and 15.6% had probable posttraumatic stress disorder. Approximately 55.6% of survivors reported at least one unmet need. Strength of unmet needs was associated with anxiety, depression, posttraumatic stress, poor quality of life, younger age, and increased time length since diagnosis. Anxiety, functional well-being, posttraumatic stress and emotional well-being accounted for 40.7% of variance in fear of recurrence (Urbaniec et al., 2011).

Hodgkinson et al. (2007) performed a similar study in Sydney to assess long-term psycho-social outcome among gynecologic cancer survivors. This study used a cross sectional prospective design with participants who were diagnosed at least one year prior to study start and who were disease-free at that time (n = 199). Results from this study found that the most frequently endorsed need was FCR (24%). In addition, results showed clinical levels of anxiety (29%) and 19% of participants reported symptoms consistent with posttraumatic stress disorder (PTSD). Approximately 90% of survivors reported supportive care needs, and the diagnosis of anxiety or PTSD resulted in a four-fold increase in unmet needs (Hodgkinson et al., 2007).

Armes et al. (2009) performed a multicenter, prospective survey using 66 cancer facilities in England, and discovered supportive care needs beyond the end of cancer. The sample included patients who received treatment for breast, prostate, colorectal, gynecologic cancer, and non-Hodgkin's lymphoma. One-third of participants at baseline reported five or more moderate to severe unmet needs; of these, 60% did not report improvement over the 6-month study period. Deimling (2006) found that among long-term cancer survivors, the most consistent predictor of psychosocial distress was dispositional optimism/pessimism, with more optimistic individuals reporting fewer cancer-related health worries, lower levels of anxiety, and diminished depression.

Dahl et al.'s (2013) literature review examined life after gynecologic cancer, with emphasis on quality of life (QOL), needs, and preferences in regard to follow-up. The study's systematic review was done on QOL using literature from 1995-2012 and several databases. In this review, fear of recurrence was the greatest concern, which was consistent with findings from other studies (Hodgkinson et al., 2007). In addition, among those who are in the long-term phase after cancer, association was found between coping style, QOL, depression, and anxiety (Dahl et al., 2013).

Kornblith et al. (2007) tested whether there were significant differences in psychosocial adjustment between younger and older survivors of breast and endometrial cancer. A total of 252 breast and endometrial cancer survivors participated in the study. Results demonstrated that both breast and endometrial cancer survivors were, on the whole, well adjusted. About 10.71% (n = 27) scored above 15 on the Hospital Anxiety and Depression Scale (HADS), which translated to clinical levels of anxiety or

depression. Of the 27 participants scored high on the HADS scale, 21 were from the younger group whereas six were in the older age group. In addition, younger survivors scored significantly worse than older survivors, regardless of disease, on several measures including fear of recurrence, distress about long-term breast and endometrial cancer problems, and discomfort caused by recent life events. In this study, breast cancer survivors scored worse on fear of recurrence than endometrial cancer survivors (Kornblith et al., 2007).

Bloom et al. (2007) conducted a literature review of QOL among long-term adult cancer survivors (over 5 years) with various types of cancer. One study of ovarian cancer survivors (Wenzel, 2002) found that 20% of the sample was "emotionally at-risk." Survivors in this sample reported fear of follow-up diagnostic tests (30%), fear of recurrence (22%), and fear of developing a second cancer (36%); 6% were classified as being clinically depressed. Two other articles examined cervical cancer survivors; Bradley et al., 2006 reported that nearly 28% of survivors met the criteria for clinical depression. This number was consistent with the findings from a similar study of post-treatment survivors that showed clinically relevant depression (Philip, 2012). In contrast, Lynch et al. (2008) used a prospective study among colorectal cancer survivors and found a low prevalence of clinically significant levels of PD at 6 and 12 months post-diagnosis. The study response rate of 53.2% may have impacted distress prevalence, through underrepresentation of those with more advanced cancers and underrepresentation of more distressed patients who may have declined to participate. However, Dempster et al.'s (2012) study of esophageal cancer survivors found that over one-third of survivors

reported clinically significant levels of psychological ill-health, mainly anxiety. Dempster et al.'s (2012) study surveyed a total of 484 people, of which 51% reported variance explained by anxiety and 42% reported variance explained by depression.

Several retrospective ovarian cancer cohort studies have identified residual symptoms post-diagnosis, but most cases have been in patients with recurrent cancer or advanced cancer. Matulonis et al. (2008) interviewed 58 survivors of early-stage ovarian cancer survivors using standardized measures to assess physical, psychological, social, and sexual functioning; impact of cancer on socioeconomic status; and complementary therapy use. Psychological assessment yielded a subset of 26% of patients with scores suggestive of posttraumatic stress disorder (PTSD), and 40% of survivors scored below the norm on the Mental Health Inventory-17. One-third of patients required treatment for family or personal problems and were prescribed anti-anxiety medications. About 59% of survivors reported anxiety when their cancer marker, CA 125 was tested.

Due to widespread screening programs, most cases of cervical cancer are being diagnosed in their early stages and with good prognoses. Despite better survival rates, the survivors of cervical cancer may continue living with its sequelae (Zeng et al., 2011). Lockwood-Rayermann (2006) reviewed 28 studies that broadly examined the psychological issues in patients with gynecologic cancers. This review indicated that among psychological sequelae of ovarian cancer, significant levels of depression and anxiety, behavioral disruptions, and emotional distress were observed—even in patients who achieved complete remission two years post-treatment. Moreover, Cain et al. (1983) found that women with ovarian cancer had significantly greater symptoms of depression

and social impairment. In contrast, Roberts et al. (1992) reported that patients with gynecologic cancer were not at any increased risk for psychological problems.

Clearly, psychological well-being is an important contributor to overall quality of life in cancer survivors (Bloom, 2002; Dempster et al., 2012; Ferrell et al., 2003). Although consensus has not been achieved, most of the research on the psychological impact of gynecologic cancer survivorship among women has shown that they experience some form of PD. It has also been shown that psychological interventions can help people with cancer to cope better with distressing situations, improve their affective state, and help to reduce the adverse effects of disease or its treatment while positively affecting quality of life (Fawzy, 1999). Therefore, it is important to study the psychological sequelae of the cancer experience. Additionally, PD is treatable and early detection and interventions could improve the overall well-being and quality of life of gynecologic cancer survivors. Nurses play a key role in helping patients cope with cancer and treatment sequelae by focusing on those specific elements of PD (Nail, 2001). Furthermore, as more Advanced Practice Nurses (APNs) care for cancer survivors, it is important to recognize how PD is related to IP and FCR among gynecologic cancer survivors as they continue their journey through the survivorship phase.

FEAR OF CANCER RECURRENCE

As previously demonstrated, FCR has been a common problem for many survivors, disrupting the psychological aspects of life and interfering with quality of life, enjoyment of life, and sense of well-being (Bradley et al., 2006; Cimprich et al., 2002; Urbaniec et al., 2011; Wenzel, 2002). It has been shown that a high FCR may be

correlated with syndromes such as post-traumatic stress disorder in long-term survivors (Mehnert et al., 2009). FCR has been found to be a significant emotional burden in prostate cancer and several cancers—including breast, gynecologic, and orofacial cancers (Hong, 2010). The Survivors of Cancer Study-I (SCS-I) reported that about 59.8% survivors were concerned about cancer recurrence (Baker et al., 2005). Due to this high prevalence of FCR, the Institute of Medicine (IOM) has prioritized helping survivors understand and manage their fears (Hewitt et al., 2006).

Studies have shown that FCR is prevalent among gynecologic cancer survivors and is the most reported unmet supportive care need among all cancer survivors. Greater perceived risk of cancer recurrence has been found to be associated with increased cancer worry among gynecologic cancer survivors (Goncalves, 2010) and breast cancer survivors (Phillips et al., 2012). Wenzel (2002) investigated quality of life concerns and survivorship sequelae of long-term (>5 year) early-stage ovarian cancer survivors and determined a significant amount of distress was related to recurrence of their cancer (22%) and fear of a second cancer (36%). In a similar study involving early-stage ovarian cancer survivors by Matulonis et al. (2008), approximately 56% of survivors were reported to have FCR.

Urbaniec et al. (2011) explored PD and unmet supportive care needs among gynecologic cancer survivors, concluding that anxiety, functional well-being, posttraumatic stress and emotional well-being accounted for 40.7% of the variance in FCR. Hodgkinson et al. (2007) conducted a similar study involving 199 gynecologic cancer survivors using a cross sectional prospective design. They found that the most

endorsed need among this group was FCR (24%). Findings from this study were consistent with Dahl et al.'s (2013) results, which found FCR to be of greatest concern.

Most research on FCR has been done among non-gynecologic cancer survivors. Impacts of ethnicity and health experiences on FCR were explored by Janz (2011) using a breast cancer sample. Women with non-metastatic breast cancer were surveyed, with a mean 9 months post-diagnosis, and 2,290 individuals responded (73%). Less acculturated Latina breast cancer patients were found to be vulnerable to high levels of FCR (Janz, 2011). Liu et al.'s (2011) investigation of breast cancer survivors found that younger age, lower social support, and elevated anxiety were associated with higher FCR at 2-year follow-up. Ziner et al. (2012) also found that breast cancer survivors diagnosed at a younger age had significantly higher FCR. Petzel et al. (2012) conducted a cross-sectional study of FCR in patients who were disease-free after a potentially curative pancreatectomy. Of 354 eligible patients, 240 (68%) participated in the study, with a median of 48 months following potentially curative pancreatectomy. FCR represented a significant concern for one-third of patients in this group after curative surgery, regardless of their actual likelihood of recurrence or disease-related death (Petzel et al., 2012).

As emphasized by IOM, the prevalence of FCR suggests that oncology professionals should describe the construct and its prevalence, and subsequently test interventions to help cancer survivors manage this problem (Ziner et al., 2012). From the literature, it is clear that FCR is a known problem for many survivors that interferes with QOL, enjoyment of life, and well-being in general (Bradley et al., 2006; Cimprich et al.,

2002; Liu et al., 2011; Urbaniec et al., 2011; Wenzel, 2002). However, it is unclear how FCR may be related to gynecologic cancer survivors' PD.

ILLNESS PERCEPTION

A major determinant of health-related QOL is the way in which patients perceive and respond to their illnesses (Hirsch et al., 2009). Emotional adjustment to cancer survivorship may be influenced by how patients interpret treatment side-effects and other cancer-related experiences (Traeger, 2009). Studies have shown that appraisal, or one's evaluation of the meaning of the cancer experience, has emotional and behavioral consequences for survivorship (Bowman, 2003). It has been established that IP can be influenced by individuals' emotional state and vice-versa (Dempster et al., 2011).

Various theories and models have addressed IP as an important factor for adjustment. Most studies regarding IP are based on Leventhal et al.'s (2003) Self - Regulatory Model of illness (SRM). This model posited that patients are problem solvers who make sense of their illness by developing their own cognitive representation, which ultimately determines how they respond behaviorally and emotionally to their illnesses (Leventhal et al., 2003). The central notion is that patients' illness beliefs guide their coping behavior, both in physiological and emotional responses to health threats. According to the SRM, the IP has five components, which include *identity* (label and the symptoms of their illness), *timeline* (duration of the illness), *consequences* (the effects and outcome of the illness), *causes* (etiology), and *control/cure* (capacity to control and cure the illness). Emotional responses to illnesses develop in parallel to the cognitive

representations, which influence and are influenced by cognitive representations (Leventhal et al., 2003

IP can explain a great proportion of variance in PD among patients of head and neck cancer (Scharloo et al., 2005) and breast cancer (Millar et al., 2005). Jorgensen et al. (2009) examined IP and psychological adjustment among women who survived breast cancer and attended a psychosocial rehabilitation course. A total of 177 survivors (145 from a descriptive study and 32 from a randomized trial) were analyzed. In this study, survivors from the descriptive study and the half of the randomized survivors attended a 1-week rehabilitation course. The remainder of the sample received standard care alone without intervention. Baseline analyses of the data indicated association between IP and distress (Jorgensen et al., 2009). A total of 26% of the variance in general distress was explained by IP at baseline. Emotional response to the illness and the belief that the illness was caused by stress or worries was significant (i.e., 22% of the variance). The results also indicated that IPs were associated with adjustment; however, IPs did not change after participation in one-week rehabilitation course (Jorgenen, 2009).

Dempster et al. (2012) conducted a similar study among esophageal cancer survivors to investigate the extent to which IPs explained PD (e.g., anxiety, depression) relative to demographic and biomedical variables. This study also examined the nature and degree to which coping strategies influenced or mediated these relationships. A total of 484 people responded to the study; data analysis indicated 51% of the variance in anxiety and 42% of the variance in depression. Perceptions of esophageal cancer explained the majority of this variance. Findings from this study suggest that cognition-

based interventions could be used to minimize the emotional distress experienced by survivors of esophageal cancer (Dempster et al., 2012).

Rees et al. (2004) used Leventhal et al.'s (2003) model to study the distress experienced by women who were at increased risk for breast cancer. Data from 117 women at increased risk of breast cancer and 100 comparison women from the general population who has no personal or family history of breast cancer were analyzed. Women at increased risk of breast cancer showed comparable levels of general distress but significantly higher levels of cancer-specific distress than the comparison group. There were few differences in IP between samples, although several cognitive perceptions of breast cancer were related to both general and cancer-specific distress in the increased risk sample.

Traeger et al. (2009) examined cognitive representations of illness in men treated for localized prostate cancer. The Perceived Stress Scale, Expanded Prostate Cancer Index Composite, Illness Perception Questionnaire-Revised, and Functional Assessment of Cancer Therapy were administered to 214 men within 18 months of completing treatment for early stage prostate cancer. Within this treatment time frame, more severely perceived consequences of prostate cancer were associated with poorer emotional well-being, particularly among men experiencing greater life stress. This study suggested that interventions that target distortions in IP may enhance emotional adjustment among survivors.

Corter et al. (2013) examined the associations between FCR and IP, medication beliefs, and treatment side effects in women taking adjuvant endocrine therapy following breast cancer. A total of 153 post-menopausal women with early-stage breast cancer completed a mail-based survey. Results indicated that all IPs (apart from personal control) were associated with FCR, as were patient beliefs about endocrine therapy. Although treatment side-effects, unemployment, and higher levels of anxiety and depression were associated with FCR, only IPs (identity, treatment control, timeline, and emotional representation) and medication necessity beliefs were significantly correlated with FCR in the final model (Corter et al., 2013).

No studies were found in the literature that explored IP among gynecologic cancer survivors. Studies involving different cancer populations have suggested that post-treatment emotional well-being may be influenced by cancer beliefs and expectations (Traeger et al., 2009). Studies on IP in patients of varying illness types have provided empirical support that patients' illness theories are critical to successful adaptation to medical illness. Research to-date has supported the relation between IP and FCR as well as overall PD. However, limited research has explored the relationship of IP and PD among gynecologic cancer survivors.

CONCLUSION

Cancer survivors may continue to experience PD decades after diagnosis and treatment (Bloom, 2002), and stressors associated with cancer may persist long after treatment has ended (Diemling, 2006). Studies have shown that PD is prevalent among gynecologic cancer survivors (Goncalves, 2010), and that IP and FCR have been

associated with PD (Hong, 2010; Millar et al., 2005; Scharloo et al., 2005). However, limited data exists to explain how these variables are related to one another in gynecologic cancer survivors. The lack of such knowledge does not allow scientists to fully understand PD among women survivors of gynecologic cancer. It is also known that psychological interventions can help people with cancer to cope better with distressing situations, improve their affective state, and help to reduce the adverse effects of disease or its treatment while positively affecting quality of life (Fawzy, 1999). Furthermore, as more APNs care for cancer survivors, it is important to recognize how PD is related to IP and FCR among gynecologic cancer survivors as they continue their journey through the survivorship phase. It is anticipated that conducting this research will contribute to 1) further understanding of PD among gynecological cancer survivors; and 2) the development of interventions for women cancer survivors to manage PD.

Chapter 3: Research Design and Methods

INTRODUCTION

This chapter presents a review of the research objective, the specific aims, and the underlying questions posed to accomplish these aims. This section includes a description of the research methods undertaken for this study including the sample, description of the instruments, and data collection and statistical procedures used to analyze the data. An exploratory, descriptive research approach was used to address the aims of this study and explore the relationship between psychological distress (PD), illness perception (IP) and fear of cancer recurrence (FCR) among gynecologic cancer survivors.

OBJECTIVE

The overall objective of this study was to explore the relationship between IP, PD, and FCR among gynecologic cancer survivors living in a community. The central theme was that gynecologic cancer survivors' IP and FCR in combination with select demographic variables can predict their PD. The rationale underlying the study was that relatedness of IP, FCR, and PD would provide a foundation for the development of interventions to assist in addressing PD among women survivors of gynecologic cancer.

METHODS

Research Design

An exploratory, cross-sectional descriptive research approach using a web-based survey was used to explore the relationship between IP, PD, and FCR among gynecologic cancer survivors.

Sample and Setting

The setting for this study was the Internet and clinical facilities providing follow-up care for cancer survivors. The clinical facilities included private physicians' office, UTMB Health Clinic (UHC), and a Specialty Care Center in southeast Texas; these sites were used to post the study flyer. In addition, five cancer support group websites (i.e., aboutcervicalcancer.com, MyLifeLine.org Cancer Foundation, IHadCancer.com, the cancer forum, foundation for women's cancer) were used as data collection sites. A Facebook account owned by the PI was also used to announce this study.

The sample consisted of women who were survivors of uterine/endometrial, ovarian, and cervical cancer. A non-probability convenience sampling method was used for this study. Power analysis was conducted using a priori sample size calculator with the lowest moderate proposed effect size of r = 0.3, alpha at .05, and power of 0.80 (Faul et al., 2009). Based on the power analysis, a minimum sample size of 67 was required for this study. To allow for a 10% attrition rate, a sample size of 75 was chosen as the target for this study. The response rate for this web-based study far exceeded the expectation of the proposed sample size of 75 subjects. A total of 632 women responded to this survey and 376 women were found eligible to participate in the study. Other women were either automatically removed from the survey because they did not meet the eligibility criteria or some subjects decided not to proceed with the survey. Of the 376 eligible subjects, 352 completed all four questionnaires and the remainder of the subjects only partially completed the survey. A sample size of 352 was used for final analysis. Further IRB

approval was obtained to include the data from the subjects beyond the proposed sample size of 75.

Inclusion/Exclusion Criteria

Women 21 years or older with a history of uterine/endometrial, ovarian, or cervical cancers and who had been disease-free for at least 2 years since treatment completion for cancer were invited to participate. Women were excluded if they were younger than 21 years of age, non-English reading/writing, history of a vulvar/vaginal cancer, or a history of non-gynecologic cancers.

Procedure

After obtaining approval from the initial Institutional Review Board (IRB) of the University of Texas Medical Branch at Galveston, Texas, a survey link for this study was created in SurveyMonkey to upload the four questionnaires: a demographic questionnaire, the Brief Illness Perceptions Questionnaire (BIPQ), Fear of Recurrence/Relapse Scale (FOR), and the Impact of Events Scale (IES). Gynecologic cancer survivors were invited to participate in this web-based survey by placing the recruitment flyers in clinical facilities, including a private physician's office, University Health Clinic (UHC) for women's health care, and a Specialty Care Center located in southeast Texas. In addition, five cancer support group websites (i.e., aboutcervicalcancer.com, MyLifeLine.org Cancer Foundation, IHadCancer.com, the cancer forum, the foundation for women's cancer) were used for the recruitment. Following IRB approval, the owners or web managers for three websites

(aboutcervicalcancer.com, MyLifeLine.org Cancer Foundation, IHadCancer.com) were provided with the study information; the study announcement and the survey link were then posted on their respective websites. The cancer forum approved a research posting request and provided temporary access to post the study information on their website. Access to the foundation for women's cancer (FWC) was obtained after the IRB approval was amended to add new recruitment sites for improved recruitment. After completing the necessary paperwork, the FWC staff directly emailed the study announcement and the survey link to their members. Participation in the study was voluntary and consent was implied through question answering. To preserve anonymity, a signed consent was waived. The data collection period was between March 23, 2013 and May 17, 2013.

Data Analyses

Data collected from the subjects included age, race, diagnosis, disease free interval since treatment completion, IP, FCR, and PD. Data was analyzed using SPSS (Version 21.0), and significance was calculated at $\alpha = .05$. All data were examined for normality and homogeneity. To examine differences between age groups (younger versus older), age was dichotomized using mean split. Ethnicity was dichotomized (White versus non-White*)* due to small sample sizes in minority groups which required collapsing categories in order to evaluate the difference between ethnic groups effectively. Survivorship was measured as both an interval variable based on the number of disease-free years (survivorship duration) and a dichotomous variable (survivorship status; early survivor, 2-5 years vs. long-term survivor, > 5 years since treatment completion). Analyses completed are described by research questions below.

SPECIFIC AIM 1

Explore the characteristics of PD, IP, and FCR across age groups, survivorship status (early survivor, 2-5 years vs. long-term survivor, >5 years) and racial/ethnic groups (White versus non-White).

Aim 1, Research Question 1

What is the distribution characteristics of PD, IP, and FCR across age groups, survivorship status (early survivor, 2-5 years vs. long-term survivor, >5 years), and racial/ethnic groups (White versus non-White)?

Analyses included descriptive statistics (i.e., mean, range, standard deviation). These statistics were used to describe each variable for the total group, across age groups, survivorship status, and racial/ethnic groups.

SPECIFIC AIM 2

Explore the relationships between PD, IP, and FCR with age and survivorship duration (number of disease-free years) within racial/ethnic groups.

Aim 2, Research Question 1

What is the relationship between PD, FCR, and IP with age, survivorship duration (number of disease-free years), within racial/ethnic groups (White versus non-White)?

Analysis included a computation of Pearson correlation coefficient between PD, FCR, and IP with age and survivorship duration within each racial/ethnic group (White versus non-White).

Aim 2, Research Question 2

What are the differences in PD, IP, and FCR across age groups, survivorship status (early survivor, 2-5 years vs. long-term survivor, >5 years), and racial/ethnic groups (White versus non-White)?

Analysis included t-tests which examined the difference in PD, IP and FCR across age groups (younger versus older). Additionally, a Mann- Whitney U analysis was used to examine the differences in PD, IP, and FCR across survivorship status, and racial/ethnic groups.

Aim 2, Research Question 3

Do IP, FCR, age, and survivorship duration predict PD across race/ethnicity among gynecologic cancer survivors?

A stepwise forward and backward multiple regression was used to evaluate whether IP, FCR, age, race/ethnicity (White versus non-White), and survivorship duration predict PD among gynecologic cancer survivors.

INSTRUMENTS

Four questionnaires were used in this study. These questionnaires included a demographic survey, The Brief Illness Perception Questionnaire (BIPQ), Fear of Recurrence/Relapse Scale (FOR), and The Impact of Events Scale (IES). The demographic survey included participants' age, race, diagnosis, and disease-free interval since treatment completion for cancer. These demographic variables were used to describe the sample and explore relationships between other study variables.

The Brief Illness Perception Questionnaire (BIPQ)

IP was assessed using the Brief Illness Perceptions Questionnaire (BIPQ) (Broadbent et al., 2006). The BIPQ has nine items: eight illness representation items and a causal scale. All of the items except for the causal question were rated using a 0-10 response scale, with a higher score indicating stronger endorsement of that item. Five of the eight items assessed cognitive illness representations: consequences (Item 1), timeline (Item 2), personal control (Item 3), treatment control (Item 4), and identity (Item 5). Two of the eight items assessed emotional representations: concern (Item 6) and emotions (Item 8). One item assessed illness comprehensibility, or how well a person understands his or her illness (Item 7). Scores of three items (3, 4, and 7; personal control, treatment control, and coherence, respectively) were reversed scored to obtain the same response direction as the other five items (1, 2, 5, 6, and 8). A summary score calculated by adding the first eight BIPQ individual items reflected the overall positivity or negativity of individuals' IPs. A higher score reflected a more threatening view of the illness. Item nine was an assessment of the causal representation by open-ended response, which asked patients to list the three most important causal factors in their illnesses. Because research questions were not developed based on this item, BIPQ-9 item was not included in the analysis of this study. Previous research demonstrates that the BIPQ items has a test–retest reliability ranging from .48 to .75 over 6 weeks in a renal patient sample ($p<.001$), and good concurrent validity with other relevant measures (e.g., Illness Perception Questionnaire-Revised). Also, sound predictive validity was noted in patients recovering from myocardial infarction (MI). A multivariate analysis of variance found that those MI patients who attended rehabilitation classes had a higher identity score at

hospital discharge than those who did not attend classes [F (39, 1) = 5.11, P = .03]. A slower return to work was significantly associated with higher concern (r =.43; P = .03) and with higher treatment control beliefs (r = .44; P = .03) (Broadbent et al., 2006). The BIPQ had a good reliability (Chronbach's alpha = .88) in a study that investigated diabetic patients' IP, adherence to treatments, and blood glucose control (Broadbent et al., 2011). Nunnally and Bernstein (1978) suggested a value of .70 as an acceptable lower bound for alpha, while DeVellis (2012, p.109) indicated that alpha scores between .70 and .80 were respectable.

Fear of Recurrence/Relapse Scale (FOR)

Kornblith et al. (1997) developed the Fear of Recurrence/Relapse Scale, which consists of five items that measures patients' belief and anxiety concerning their disease recurring relevant to cancer survivor populations. The FOR scale was used to measure FCR in this study. This scale has been used among patients experiencing early stage disease, and with patients who are being followed after treatment completion (Greenberg et al., 1997). All items in this scale were rated on a 5 point Likert scale (1 = strongly agree, 2 = agree, 3 = not certain, 4 = disagree and 5 = strongly disagree). For scoring, items 1, 2, 3, 4 were reverse coded and items summed (range of possible scores =5-25) so that higher scores indicated greater fear of recurrence. The FOR Scale has been used among childhood cancer survivors (Hill et al., 1998) and adult leukemia survivors (Greenberg et al., 1997). The FOR scale is reported to have a good internal consistency (alpha coefficient = .73) (Greenberg et al., 1997), reported .78 in a breast and endometrial cancer survivor study (Kornblith et al., 2007), and reported .83 in an ovarian cancer

survivor study (Matulonis et al., 2008). Also, the FOR scale has shown some evidence of convergent validity. This scale was significantly correlated albeit of small magnitude, with relevant emotional state subscales of the Brief Symptom Inventory (BSI), the Depression subscale ($r = .24$, $p = .01$), and Paranoid Ideation subscales ($r = .19$, $p < .05$), and also correlated with the Derogatis Body Image subscale ($r = .31$, $p < .001$) in the childhood leukemia survivors study (Hill et al., 1998). Further evidence of validity was found in Mehta et al.'s (2003) study in which general health perceptions demonstrated small but significant correlations with fear of recurrence, i.e., the higher the ratings of patient health, the lower the reports of fear of recurrence ($r = .27$, $p < .001$) (Mehta et al., 2003).

Impact of Events Scale (IES)

The IES scale is a self-report measure designed to assess current subjective distress for specific life events (Horowitz et al., 1979). This scale was used to measure PD in this study. The IES scale consisted of 15 items, seven of which measure intrusive symptoms (intrusive thoughts, nightmares, intrusive feelings and imagery) and eight items measure avoidance symptoms (numbing of responsiveness, avoidance of feelings, situations, ideas). When these individual items were combined, they provided a total subjective distress score. Respondents were asked to rate the items on a 4-point scale to reflect how often each item has occurred in the past seven days: 0 (not at all), 1 (rarely), 3 (sometimes), and 5 (often). The scores for the intrusive subscale ranged from 0 to 35, equal to the sum of the scores for items 1, 4, 5, 6, 10, 11, and 14. The scores for the avoidance subscale ranged from 0 to 40, equal to the sum of the scores for items 2, 3, 7,

8, 9, 12, 13, and 15. The sum of the two subscales is the total stress score, which ranged from 0-75. A score above 27 was considered the point at which a moderate or severe effect is indicated (Coffey, 2006). Corcoran and Fischer (1994) found that the subscales of the IES showed very good internal consistency based on two separate sample groups of outpatients treated for bereavement over the course of treatment. The coefficients ranged from .79 to .92. This sensitivity to movement was reported by Horowitz et al.'s (1979) study of 32 subjects with stress response syndromes. The IES was administered twice to each subject with a mean time of 11 weeks between first and second administration. A split-half reliability for the whole scale was .86 (Horowitz et al., 1979). Results indicated a test-retest reliability of .87 for the total stress scores .89 score for the intrusion subscale, and .79 score for the avoidance subscale (Horowitz et al., 1979). In addition, Horowitz et al.'s (1979) study compared the IES scores between a sample of patients who had experienced specific traumatic life events and a sample of medical students who were exposed to cadaver dissection. Result showed a major difference in effects between the groups for intrusion ($F = 212.1$, $p < 0.0001$), for avoidance ($F = 73.0$, $p < 0.001$) and for the total score ($F = 170.8$, $p < 0.0001$) (Horowitz et al., 1979). A more recent study reported the IES to have good internal consistency, as measured by Cronbach's alpha .86 (Coffey, 2006).

In summary, an exploratory, cross-sectional descriptive research approach using a web-based survey was used to explore the relationship between IP, FCR, and PD among gynecologic cancer survivors. The final sample used for analyses was 352. Results will be presented in the next chapter.

Chapter 4: Results

INTRODUCTION

This chapter describes the results of the study that examined the relationship between illness perception (IP), fear of cancer recurrence (FCR), and psychological distress (PD) among gynecological cancer survivors. Descriptions of the demographic characteristics of the sample as well as psychometric properties of the instruments used in this study are presented in this section. Findings for each research question are addressed separately.

The overall objective of this study was to explore the relationship between IP, FCR, and IP among gynecologic cancer survivors living in a community. The central theme of this study was that gynecologic cancer survivors' IP and FCR in combination with select demographic variables could predict their PD.

The dependent variable for this study was PD. The independent variables were demographic factors (age, race, and diagnosis), disease-free interval since treatment completion, IP, and FCR. PD was measured using the Impact of Events Scale (IES), IP was measured by the Brief Illness Perception Questionnaire (BIPQ), and FCR was measured using the Fear of Recurrence/Relapse (FOR) scale. Survivorship was measured using 1) survivorship status (early survivors, 2-5 years vs. long-term survivors, >5 years), a dichotomous variable and, 2) survivorship duration (number of disease-free years), an interval variable.

DESCRIPTION OF THE SAMPLE

Six hundred thirty-two women responded to the survey. Of these women, 376 eligible subjects answered portions of the questionnaires, and 352 subjects completed all of the questionnaires. For the analysis of this study, 352 subjects with completed questionnaires were included. Demographic breakdowns across characteristics for the total sample are shown in Tables 4.1, 4.2 and Figure 2. The age range was 51 with a minimum and maximum age of 29 and 80, respectively, and a mean of 57.07 years (SD = 10.116). The range of disease-free intervals since treatment completion (survivorship duration) was 28 years (minimum of 2 years and a maximum 30 disease-free years), with a mean of 5.65 years (SD = 4.707).Women responding to this survey were from five different races/ethnicities, including non-Hispanic White (88.9%), Hispanic White (3.7%), African American/Black (1.4%), Hispanic (2.3%), and Asian (3.7%). A majority of the subjects were survivors of ovarian cancer (59.7%), followed by uterine/endometrial cancer survivors (31.3%), and cervical cancer survivors (9.1%) (see Figure 2).

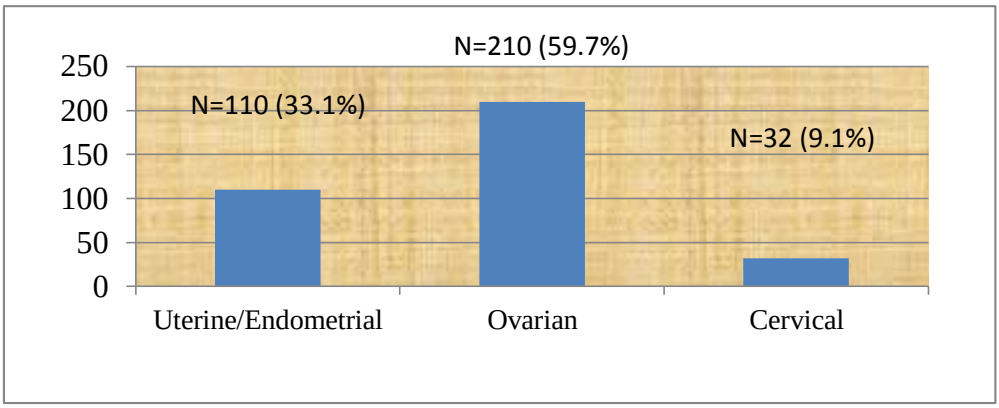
Table 4.1: Demographic characteristics (n = 352)

Variable	*M*	*SD*
Age (± *SD*)	57.07	10.116
Disease free interval (± *SD*)	5.65	4.707

Table 4.2: Demographic Characteristics (n= 352)

Variable	*n*	*%*
Race/Ethnicity		
Non-Hispanic White	313	88.9
Hispanic White	13	3.7
African American/Black	5	1.4
Hispanic	8	2.3
Asian	13	3.7

Figure 2: Distribution of Survivors by Diagnoses (n=352)



PRELIMINARY ANALYSES

To conduct further analyses, several variables were dichotomized and a frequency analysis was conducted to describe the distribution characteristics of these variables for the reconstituted groups and across racial/ethnic groups (Tables 4.3 and 4.4).

Table 4.3: Distribution of Race/Ethnicity, Age Groups, and Survivorship Status Across Reconstituted Groups (n = 352)

Variables	*n*	*%*
Race/Ethnicity		
White	326	92.6
Non-White	26	7.4
Age groups		
29-57	166	47.2
58-80	186	52.8
Survivorship status		
Early survivor	231	65.6
Long-term survivor	121	34.4

Because race/ethnicity data did not provide meaningful or generalizable findings due to racial/ethnic group sizes of less than 20 in each subcategory except for non-Hispanic White, race/ethnicity was divided into White (92.6%) and non-White (7.4%). All racial/ethnic groups except non-Hispanic White were combined to form one group of non-White (N = 26) for use in subsequent analyses. To examine differences between age groups, two age groups were created using a mean split (age 57): age 29-57 (47.2%) and age 58-80 (52.8%). Survivorship status was measured using the number of disease-free years from treatment completion. Disease-free years from treatment completion were divided into two groups to compare differences between early survivors and long-term survivors. Individuals who were disease-free for 2-5 years from treatment completion

were considered early survivors, and those individuals who were disease-free for more than 5 years were considered long-term survivors. There were more early survivors (65.6%) than long-term survivors (34.4%).

Table 4.4: Distribution of Diagnoses, Age Groups, and Survivorship Status across Race/Ethnicity

Variables	White (n=326)	Non-White (n=26)
	n (%)	
Diagnoses		
Uterine/Endometrial	101 (91.8)	9 (8.2)
Ovarian	194 (92.4)	16 (7.6)
Cervical	31 (96.9)	1 (3.1)
Age groups		
29-57	151 (91)	15 (9)
58-80	175 (94.1)	11 (5.9)
Survivorship status		
Early survivor	213 (92.2)	18 (7.8)
Long-term survivor	113 (93.4)	8 (6.6)

PSYCHOMETRIC PROPERTIES OF THE INSTRUMENTS

First, reliability of each scale (The Brief Illness Questionnaire, Fear of Cancer Recurrence Scale, and The Impact of Events Scale) for this study sample was calculated using the Cronbach's alpha coefficient; those results are depicted in Table 4.5. These

instruments were found to have respectable reliability in this study. Cronbach's alphas for this study were consistent with previous research using these instruments. For example researchers who investigated diabetic patients' perceptions of illness, adherence to treatments, and blood glucose control using BIPQ had a Cronbach's alpha of .88 (Broadbent et al., 2011). Similarly, reliability for other instruments used in this study was also consistent with previous studies. For example Kornblith et al. (2007) reported reliability for the FOR scale of .78, and Coffey's (2006) study indicated an alpha of .86 for the IES.

Table 4.5: Instrument Reliability

Instrument	α	Number of items
BIPQ	.753	8
FOR	.845	5
IES	.892	15

DATA ANALYSES

Following reliability verification, the research questions corresponding to study aims were examined. Since the variable of race/ethnicity was collapsed into two categories (White and non-White), the resulting groups represent grossly unequal samples (White=326 and Non-White=26) which has implications for study analyses and power, i.e., larger effect sizes would be required for the Non-White group to achieve

significance. Therefore, a more useful and appropriate focus will be on effect size rather than simple statistical significance.

Specific Aim 1: The first aim of the study was to explore the characteristics of PD, IP, and FCR across age groups, survivorship status (early survivor, 2-5 years vs. long-term survivor, >5 years) and racial/ethnic groups (White versus non-White).

Research Question 1.1

The first research question was to determine the distribution characteristics of PF, IP, and FCR across age groups, survivorship status (early survivor, 2-5 years vs. long-term survivor, >5 years) and racial/ethnic groups (White vs. non-White). First, total scale scores were calculated for each scale that measured the respective variables.

Descriptive statistics (i.e., mean, range, standard deviation) were then calculated to examine the distribution of each variable (PD, IP, and FCR) across racial/ethnic groups, age groups, and survivorship status. Statistical comparisons across groups will be addressed in Research Question 2.2. Table 4.6 displays descriptive statistics for these variables across race/ethnicity. The mean score for PD for non-Whites was lower than Whites indicating that non-White participants reported lower psychological distress than White participants. Similarly, the mean score for FCR was also lower for non-Whites compared to Whites suggesting that non-White gynecologic cancer survivors reported a lower fear of cancer recurrence than White survivors. In addition, the results demonstrated a lower mean score for IP among non-Whites than Whites reflecting a lower illness perception among non-Whites compared to White participants.

Table 4.6: Mean, Range and Standard Deviation for Psychological Distress, Fear of Cancer Recurrence, and Illness Perception across Racial/Ethnic Groups

Variables*	n	Mean	SD	Range
PD total score				
Non-White	26	24.92	17.05	59.00
White	326	26.05	15.88	66.00
FCR total score				
Non-White	26	11.96	4.56	16.00
White	326	13.79	4.73	20.00
IP total score				
Non-White	26	30.69	15.73	59.00
White	326	32.25	13.93	71.00

*PD = Psychological distress, FCR = Fear of cancer recurrence, IP = Illness perception

When examining age groups, descriptive statistics revealed that the gynecologic cancer survivors from the older age group had lower mean scores for PD and IP than did younger age groups indicating that older survivors experienced less psychological distress and illness perception than younger survivors . The FCR score was only slightly higher among the younger age group than the older age group reflecting a slightly higher fear of cancer recurrence reported by younger gynecologic cancer survivors (Table 4.7).

Table 4.7: Mean, Standard Deviation and Range of Psychological Distress, Fear of Cancer Recurrence and Illness Perception across Age Groups

Variables	n	Mean	SD	Range
PD total score				
Age 29-57	166	28.55	16.47	66.00
Age 58-80	186	23.67	15.14	65.00
FCR total score				
Age 29-57	166	14.25	4.45	20.00
Age 58-80	186	13.13	4.94	20.00
IP total score				
Age 29-57	166	35.87	13.10	59.00
Age 58-80	186	28.80	14.08	71.00

Descriptive statistics were also used to examine the distribution of the scores on the instruments that measured variables of PD, FCR, and IP across survivorship status (Table 4.8). For this study, survivorship status was measured using number of disease-free years since treatment completion which was then dichotomized into two groups based on the number of disease-free years. Those who have been disease-free for 2-5 years were considered early survivors and those who were disease-free for over 5 years since treatment completion were considered long-term survivors. When examining survivorship, descriptive statistics revealed a higher PD, FCR and IP mean score among early survivors than long-term survivor which most likely reflect that lesser time since

treatment completion for early survivors was associated with higher psychological distress, fear of cancer recurrence and illness perception.

Table 4.8: Mean, Standard Deviation, and Range of Psychological Distress, Fear of Cancer Recurrence and Illness Perception across Survivorship Status

Variables*	n	Mean	SD	Range
PD total score				
Early survivor	231	29.10	15.71	66.00
Long-term survivor	121	19.98	14.67	59.00
FCR total score				
Early survivor	231	14.53	4.69	20.00
Long-term survivor	121	11.99	4.39	20.00
IP total score				
Early survivor	231	35.13	13.61	67.00
Long-term survivor	121	26.41	13.13	64.00

*PD = Psychological distress, FCR = Fear of cancer recurrence, IP = Illness perception

Specific Aim 2: The study's second aim was to explore the relationships between PD, IP, and FCR with age and survivorship duration (number of disease-free years) within racial/ethnic groups.

Research Question 2.1

RQ 2.1 explored the relationship between PD, FCR, and IP with age and survivorship duration within each racial/ethnic group (White versus non-White). All variables that were examined under this research question met the assumption of interval level data. Therefore, a Pearson correlation coefficient was calculated between PD, FCR, and IP with age and survivorship duration for both racial/ethnic groups (Table 4.9).

Table 4.9: Correlation of PD, FCR, IP with Age and Survivorship Duration across Racial/Ethnic Groups

Variables	Non-White (n = 26) r	White (n = 326) r
PD		
Age	-.317	-.238**
Survivorship duration	-.362	-.274**
FCR		
Age	-.485*	-.144**
Survivorship duration	-.229	-.317**
IP		
Age	-.672**	-.271**
Survivorship duration	-.389*	-.263**

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

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

The correlation coefficient results demonstrated an overall pattern of negative correlations between PD, FCR, and IP with age and survivorship duration among both Whites and non-Whites. These results indicated that as age and survivorship duration increased, PD, FCR, and IP decreased. When examining age, this variable showed a moderate to strong correlation with all three study variables for non-Whites although the relationship with PD failed to reach significance largely due to the small sample size. Conversely the pattern of relationships between age and all three study variables for Whites did reach significance but represent extremely small effect sizes. When considering survivorship duration, this variable showed larger correlations with PD and IP among non-Whites compared to Whites.

Research Question 2.2

RQ 2.2 explored the differences in PD, IP, and FCR across age groups, survivorship status, and racial/ethnic groups (White versus non-White).

The differences in PD, FCR, and IP across age groups—younger (age 29-57) versus older (age 58-80) was examined using *t*-tests (Table 4.10). Levene's test of homogeneity indicated no significant issues with heterogeneity. A significant difference in PD, FCR and IP between the younger and older group was found, suggesting that the younger age group had experienced more psychological distress, fear of cancer recurrence and illness perception than the older age group.

Table 4.10: Test of Differences between PD, FCR, and IP across Age Groups Using *t*-test

Variables	N	M	SD	t	p
PD					
Age group 29-57	166	28.55	16.47	2.898*	.004
Age group 58-80	186	23.67	15.14		
FCR					
Age group 29-57	166	14.25	4.45	2.234*	.026
Age group 58-80	186	13.13	4.94		
IP					
Age group 29-57	166	35.87	13.10	4.866*	.000
Age group 58-80	186	28.80	14.08		

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

Next, due to the unequal and small sample sizes in ethnic and survivorship groups, the non-parametric statistical test—a Mann- Whitney U—was used to examine the differences in PD, IP, and FCR across racial/ethnic groups and survivorship status. Mann- Whitney U analysis across racial/ethnic groups on the variables found no significant differences in PD or IP (Table 4.11). However, a marginally significant difference was noted in the FCR between racial/ethnic groups, with non-Whites demonstrating a lower FCR mean rank than Whites (p=.065). Overall these findings would suggest that race/ethnicity did not make a significant difference in the psychological distress, fear of cancer recurrence or illness perception experienced by the survivors.

Table 4.11: Mann-Whitney U Test of difference PD, FCR, IP across Racial/Ethnic Groups

Variables	Race	N	Mean Rank	*U*	p
PD					
	non-White	26	167.58	4006	.642
	White	326	177.21		
FCR					
	non-White	26	141.12	3318	.065
	White	326	179.32		
IP					
	non-White	26	164.19	3918	.521
	White	326	177.48		

Mann-Whitney U results for comparisons between early versus long-term survivors or survivorship status on the PD, FCR, and IP are displayed in Table 4.12. Result showed a significant difference in PD, FCR and IP with mean ranks higher among early survivors than long-term survivors indicating that early survivors experienced more psychological distress, greater fears of recurrence and more consequences from their illness than long-term survivors ($p<.001$).

Table 4.12: Mann-Whitney U Test of Difference PD, FCR, IP across Survivorship Status

Variables	Survivorship Status	N	Mean Rank	*U*	p
PD					
	Early survivor	231	196.74	9299	<.001
	Long-term survivor	121	137.85		
FCR					
	Early survivor	231	195.53	9579	<.001
	Long-term survivor	121	140.17		
IP					
	Early survivor	231	198.48	8899	<.001
	Long-term survivor	121	134.55		

*P < .001

Research Question 2.3

The purpose of RQ 2.3 was to investigate whether IP, FCR, age, and survivorship duration predicted PD across race/ethnicity among gynecologic cancer survivors. A stepwise forward and backward multiple regression was conducted to assess the contribution of the study variables. The criterion variable was PD, while IP, FCR, age, and survivorship duration were the predictor variables. Before beginning the analysis, the assumptions of multiple regression analysis were examined. First, multiple regression assumes low correlation between predictors. Second, multiple regression assumes high correlation between predictors and criterion.

WHITE PARTICIPANTS

Pearson's correlation was conducted to determine the correlation between predictors and the correlations between predictors and the criterion among Whites. FCR and IP were found to be strongly correlated (r = .754, p = .000). While there were correlations between other predictor variables, the magnitude of these correlations was small to moderate. After examining tolerance (FCR = .410 and IP = .494) and variance inflation factors (VIF) (FCR = 2.442 and IP = 2.474), concern with multicollinearity was not supported. While the correlations between the predictor and criterion variables were small except for FCR and IP, the regression analyses were performed with the understanding of this limitation (Table 4.13).

Table 4.13: Pearson's r Correlations between Predictor Variables, and between Predictor Variables and Criterion Variable across Whites

	Age	FCR	IP	Survivorship Duration
FCR	-.144 (p=.005)			
IP	-.271 (p=.000)	.754 (p=.000)		
Survivorship Duration	.203 (p=.000)	-.317 (p=.000)	-.263 (p=.000)	
PD	-.238 (p = .000)	.565 (p = .000)	.640 (p = .000)	-.274 (p = .000)

Note: PD = Psychological distress; FCR=Fear of cancer recurrence; IP= Illness perception; Survivorship Duration= Disease free years since treatment completion; Age= Current age

Stepwise forward multiple regression was performed including each of the highly correlated predictor variables (FCR and IP) in the set separately. When FCR was excluded from the model, IP accounted for 41% of the variance in the model; when IP was excluded from the model, FCR accounted for 32% of the variance in the model. Given the greater contribution of IP to the model, FCR was dropped from the final forward regression model. The final stepwise forward multiple regression model (conducted without FCR) resulted in a predictor set of IP and survivorship duration, producing $R^2 = .421$ in which higher levels of illness perception (accounting for 61% of the variance explained) and shorter survivorship duration (11% of the variance explained) were predictive of psychological distress. Although age had a significant correlation with PD, it did not contribute significantly to the regression model. A stepwise backward regression was also conducted to verify that no variables were missed during forward regression and the findings were identical in terms of predictors, ANOVA, and R^2 values. Therefore, both stepwise forward and backward regression analyses resulted in a final predictor set of IP and survivorship duration (Table 4.15).

NON-WHITE PARTICIPANTS

Pearson's correlation was conducted among non-Whites to determine the correlation between predictors and the correlations between predictors and the criterion. The correlations between variables are described in Table 4.14. FCR and IP were found to be even more strongly correlated at $r = .813$, $p = .000$. In addition, age was strongly negatively correlated with both IP ($r = -.672$, $p = .000$) and FCR ($r = -.485$, $p = .006$). Finally, IP and survivorship duration displayed a significant negative correlation ($r =$ -

.389, p = .025) (Table 4.14). After examining tolerance (FCR = .316, IP = .186 and age = .481) and variance inflation factors (VIF) (FCR = 3.162, IP = 5.372 and age = 2.081), concern with multicollinearity was supported for IP. The correlations between all of the predictor variables and the criterion were moderate to strong, and were therefore included in the analysis given the correlation with the criterion variable.

Table 4.14: Pearson's r Correlations between Predictor Variables, and between Predictor Variables and Criterion Variable across Non-Whites

	Age	FCR	IP	Survivorship Duration
FCR	-.485 (p = .006)			
IP	-.672 (p = .000)	.813 (p = .000)		
Survivorship Duration	.063 (p = .381)	-.229 (p = .130)	-.389 (p = .025)	
PD	-.317 (p = .058)	.469 (p = .008)	.657 (p = .000)	-.362 (p = .035)

Note: PD = Psychological distress; Age = Current age; FCR = Fear of cancer recurrence IP = Illness perception; Survivorship duration = Disease-free years since treatment completion.

Stepwise forward multiple regression was performed for non-whites systematically excluding the highly correlated predictors; FCR, IP and age. When FCR was excluded from the model, IP accounted for 43.2% of the variance in the model and when IP was excluded from the model, FCR accounted for 22% of the variance. When age was excluded from the model, IP again accounted for 43.2% variance and no other variables contributed to the model. A final stepwise forward multiple regression,

conducted with all four predictor variables resulted in a predictor model with only IP being predictive of PD, R^2= .432.

A stepwise backward regression was also conducted to verify that no variables were missed during forward regression. Backward regression using all predictor variables resulted in a model with age, FCR and IP producing 47.9% variance with FCR accounting for 1.9% of the variance explained, IP accounting for 43.2%, and age accounting for 2.8%. When FCR was dropped from the model, age and IP together contributed to 46% of variance. When age was dropped from the model, IP alone resulted in 43.2% variance. Although FCR, survivorship duration and age were significantly correlated with PD, these variables did not contribute uniquely to the regression model.

The resulted predictor model with IP was identical to the forward regression. Based on the results from both forward and backward regression analyses, IP was found to be the best predictor for PD among non-whites (Table 4.15). In summary, for White participants, 42% of the variance in PD was explained by IP and survivorship duration (R^2 = .421, F (2, 323) = 117.56, p < .001). For the non-White participants, stepwise forward multiple regression resulted in a predictor model for which only IP was predictive of PD accounting for 43% of the variance.

Table 4.15: Best Predictor Model for Psychological Distress for White and non-White Participants

Variable included in the model	R^2	F value	(df)	Standardized β	p
White					
Illness perception				.610	<.001
	.421	117.561	(2, 323)		<.001
Survivorship Duration				-.113	.010
Non-White					
Illness perception	.432	18.234	(1, 24)	.657	< .001

Note: df = degrees of freedom

SUMMARY OF RESULTS

In summary, the study sample consisted of three hundred fifty-two gynecologic cancer survivors who have been disease-free for at least two years since treatment completion for cancer. A majority of women who responded to the survey were non-Hispanic White (88.9%) followed by Hispanic White (3.7%), Asian (3.7%), Hispanic (2.3%) and, African American/Black (1.4%). Since some racial/ethnic groups had sizes less than 20 in each subcategory, the race/ethnicity was divided into two groups; White (92.6%) and non-White (7.4%) for the final analyses.

Ovarian cancer survivors were the most majority who completed the survey (59.7%), followed by uterine/endometrial cancer survivors were (31.3%), and cervical cancer survivors (9.1%). More than half of the participants were early survivors (65.6%) compared to long-term survivors (34.4%). To examine differences between age groups, two age groups were created using a mean split (age 57). Participation in the survey was higher from the older survivors (58-80 years) (52.8%) than younger survivors (29-57 years) (47.2%).

Three standardized instruments with acceptable reliability were used in this study: the Brief Illness Questionnaire ($\alpha = .753$), Fear of Cancer Recurrence Scale ($\alpha = .845$), and the Impact of Events Scale ($\alpha = .892$).

Specific Aim 1 examined the characteristics of IP, FCR, and PD across age groups, survivorship status, and race/ethnicity. The mean scores for PD, FCR, and IP were lower for non-White participants than for White participants. Gynecological cancer survivors from the younger age group demonstrated a higher mean score for PD, IP, and FCR than did older age groups. However, FCR scores were only slightly higher among the younger group. Early survivors reported higher PD levels, FCR scores, and IP compared to long-term survivors.

Specific Aim 2 explored the relationship between PD, FCR, and IP with age and survivorship duration within each racial/ethnic groups (White versus non-White).

To address RQ 2.1, a Pearson correlation was performed to examine the relationship between variables. A negative correlation was noted between PD, FCR and

IP with age and survivorship duration among both White and non-White participants indicating that early survivors and younger survivors experienced more psychological distress, fear of cancer recurrence and perceived more consequences from their cancer. This finding was similar in both White and non-White participants. Age demonstrated a strong correlation with PD only among Whites indicating that age is an important factor determining PD among cancer survivors from White ethnicity. But age had a strong correlation with FCR and IP among both Whites and non-Whites indicating that age is also a determining factor for FCR and IP for White and non-White cancer survivors. Survivorship duration (number of disease-free years) had a significant correlation with PD, FCR, and IP among White participants which indicate that the number of disease-free years is an important determining factor for PD, FCR and IP among survivors from White ethnicity. However, survivorship duration was only significantly correlated with IP among non-White participants indicating that for non- White survivors, the number of disease-free years affected their IP and it had no significant impact on PD or FCR.

Research question 2.2 examined the differences in PD, IP, and FCR across age groups, survivorship status, and racial/ethnic groups. A *t*-test was used to examine differences in the above variables across age groups. Younger gynecologic cancer survivors reported a significantly greater IP, FCR, and PD than the older age group indicating that age affects cancer survivors' IP, FCR and PD and that younger survivors have more psychological distress, fear of cancer recurrence and perceive their cancer illness differently than older survivors. A Mann-Whitney U analysis was used to examine the differences in PD, IP, and FCR across racial/ethnic groups and survivorship status.

Race/ethnicity did not make a difference in PD, FCR, or IP. Results demonstrated a significant difference in PD, FCR, and IP experienced by the gynecologic cancer survivors based on survivorship status (early versus long-term survivor). This result indicates that survivorship status is a determining factor for PD, FCR and IP among cancer survivors and it also shows that early survivors have more psychological distress, fear of cancer recurrence and they perceive more consequences from the cancer illness than long-term survivors.

RQ 2.3 investigated whether IP, FCR, age, and survivorship duration predicted PD across race/ethnicity among gynecologic cancer survivors. For the White participants, IP and survivorship were the best predictors for PD. But for non-White participants, IP alone was the best predictor for PD.

Chapter 5: Conclusions, Discussion and Recommendations

INTRODUCTION

In this chapter, the results of the study and their relationship to the existing literature and to the study's conceptual framework are discussed. Limitations and recommendations for future research are presented. The chapter concludes with the implications for nursing.

DISCUSSION OF MAJOR FINDINGS

This section presents findings related to the study variables (i.e., sample demographics, survivorship, IP, FCR and PD), reliability of instruments, and results of each research question.

Sample Demographics

The sample demographics discussed in this section include age, race/ethnicity, and diagnosis.

AGE

Six hundred thirty-two women responded to the survey. Three hundred fifty-two subjects completed all four questionnaires in the survey and were included in the final analysis. The age of the subjects ranged from 29-80, with a mean age of 57.07 (SD = 10.116). This finding is similar to those of other studies. Costanzo et al. (2005) examined relationships between cancer attributes and PD and health practices among gynecologic cancer survivors in which women's age ranged from 23-90 years, with a mean age of 60

years. Hodgkinson et al.'s (2007) study assessed long-term psychosocial outcomes and supportive care needs of gynecologic cancer survivors, and average age of survivors was 59.1 years with an age range of 28-89 years. The mean age for a similar study that examined the long-term adjustment of early-stage ovarian cancer survivors was 56.2 years, with a range of 34-77 years (Matulonis et al., 2008). When the age of participants was grouped into younger and older in this study, there were a slightly higher percentage of older women (52.8%) than younger women (47.2%). These findings are similar to Ziner et al.'s (2012) study, whose younger participants (age $\leq$ 45) were fewer (45%) than older participants (age 55-70) (55%).

RACE/ETHNICITY

Five racial/ethnic groups were included in this study. A majority of women who responded to the survey were non-Hispanic White (88.9%), followed by Hispanic White (3.7%), Asian (3.7%), Hispanic (2.3%), and African American/Black (1.4%). Because racial/ethnicity data did not provide meaningful or generalizable findings due to racial/ethnic group sizes of less than 20 in each subcategory except for non-Hispanic White, race/ethnicity was divided into White (92.6%) and non-White (7.4%). In a similar study conducted among gynecologic cancer survivors, 95% of the participants were White (Costanzo et al., 2005), while other researchers had a high participation rate from non-Hispanic Whites (97%) (Matulonis et al., 2008). In addition, a Gynecologic Oncology Group (GOG) trial among long-term ovarian cancer survivors reported participation from Caucasians (89.8%) (Wenzel, 2002). The findings of this current study

suggest that the demographics are similar to other studies, with Caucasians being the majority of the participants and ranging in age from 29 – 80 years.

DIAGNOSIS

This study included survivors of ovarian, endometrial/uterine, and cervical cancers. A majority of the women in this study who completed the survey were survivors of ovarian cancer (59.7%), with uterine/endometrial cancer survivors being next at 31.3%, and cervical cancer survivors at 9.1%. In contrast, Hodgkinson et al.'s (2007) study on gynecologic cancer survivors had a higher participation from endometrial cancer survivors (45.7%), followed by ovarian cancer survivors (27.1%), cervical cancer survivors (20.1%), and vaginal/vulvar cancer survivors (7%). Furthermore, a recent report indicated that based on all cancer survivors there were 8% uterine cancer survivors, 3% ovarian cancer survivors, and 3% cervical cancer survivors (American Cancer Society, 2012). Although the literature has indicated that there tend to be higher numbers of uterine/endometrial cancer survivors, a majority of the participants in the current study was ovarian cancer survivors.

SURVIVORSHIP

For the current study, survivorship was measured using survivorship duration (number of disease-free years from treatment completion) and survivorship status (early versus long-term survivors). The mean time between treatment completion and the survey (survivorship duration) was 5.65 years, and this duration ranged from 2 to 30 years. This finding is similar to data in Matulonis et al.'s (2008) study. The mean time from the

diagnosis and the interview conducted in that study was 5.81 years, with a range of 3 to 15 years. In the current study, more than half of the participants were early survivors (2-5 years [65.6%]) compared to long-term survivors (>5 years [34.4%]).

Other Study Variables

In addition to demographic variables, other independent variables included in this study were IP and FCR. The dependent variable for this study was PD. PD was measured using the Impact of Events Scale (IES), IP was measured by the Brief Illness Perception Questionnaire (BIPQ), and FCR was measured using Fear of Recurrence/Relapse (FOR) scale.

Reliability of Instruments

Instruments used in this study had respectable reliability: BIPQ (α = .753), FOR (α = .845), and IES (α = .892). These reliability values were consistent with other studies: IES α = .90 - .91 (Norton, 2004; Wenzel, 2002), BIPQ α = .88 (Broadbent et al., 2011), and FOR α = .78 (Kornblith et al., 2007). DeVellis (2012) considered alphas between .70 and .80 for instruments as being acceptable.

AIM 1: RESEARCH QUESTION 1: DISTRIBUTION CHARACTERISTICS OF VARIABLES

Psychological Distress across Race/Ethnicity, Survivorship Status, and Age Group

In the current study, mean scores for PD was lower among non-Whites than Whites. These findings are similar to those of Deimling (2006) when studying PD (i.e., anxiety, depression) among older, long-term cancer survivors. Deimling (2006) found lower levels of distress among African Americans than Whites. Likewise, Schootman et

al. (2010) found that PD was more prevalent among Whites than African American survivors when studying racial disparities among Caucasians, African Americans, and other races. In contrast, Hoffman et al. (2009) found that race was not associated with PD among survivors. It is not fully clear why the findings are different from those of other studies. However, the author has acknowledged that the participants were identified from a National Health Interview Survey, and that their health status, disease history, type of cancer, and time at which cancer was diagnosed were self-reported. Additionally, the participants' prior individual or family mental health histories were unknown.

The results from the current study demonstrated lower PD among older participants than younger participants. Further, higher mean scores for PD were noted among early survivors than long-term survivors in the current study. Hoffman et al. (2009) explored socio-demographic and clinical factors associated with experiencing serious PD among long-term survivors of adult-onset cancer. Results showed that long-term survivors were at risk for PD; however, the sample included only long-term survivors. But when survivors were grouped by age and co-morbid illness, more than 25% of survivors younger than 45 years with co-morbid illnesses reported having serious PD (Hoffman et al., 2009). Brant (2011) examined post-chemotherapy symptom trajectories among cancer survivors over a 16-month period. Higher distress was predicted by younger age ($p < .05$); with each 1-year increase in age, distress scores decreased by 0.58. Yanez et al. (2013) examined the prevalence of, and factors associated with, distress among young adult cancer survivors (ages 18–39). The sample in Yanez et al.'s (2013) study was within 0–60 months post-treatment. Results indicated that young

adult survivors experienced clinically significant levels of distress, with the highest level of distress encountered during 13–24 months post-treatment. In contrast to this finding, Hoffman et al. (2009) found no association between number of years since cancer diagnosis and PD. This is similar to the findings by Hodgkinson et al. (2007), where number of years since diagnosis did not correlate with distress among long-term gynecologic cancer survivors. The difference in these findings could be due, in part, to the difference in when the sample participated in each study. For example, both Hodgkinson et al. (2007) and Hoffman et al. (2009) had long-term survivors, whereas Brant (2011) had examined post-chemotherapy symptoms over a short duration. The current study was tested when the survivors have transitioned into the survivorship phase, and individuals were at least 2 years disease-free since their treatment completion. The current study found that PD was lower among non-Whites than Whites, lower among older participants than younger participants, and lower among long-term survivors than early survivors.

Illness Perception across Race/Ethnicity, Survivorship Status, and Age Groups

The current study found a lower mean score for IP among non-Whites than Whites. Additionally, IP was lower among the older age group than the younger age group. These two finding suggest that non-Whites and those who are older perceive less consequences from their illnesses. IP scores were higher among early survivors than long-term survivors in the current study, suggesting that early survivors perceive their illness as one with severe consequences. Few studies have been conducted on IP among gynecologic cancer survivors. Those studies that exist have examined IP among breast

cancer, esophageal, and prostate cancer survivors. Dempster et al. (2011) examined the extent to which IP explains esophageal cancer survivors' PD (in terms of anxiety and depression). After controlling for certain demographic variables, IP and coping contributed the majority of the explained variance in PD (Dempter et al., 2011). The results showed that a great proportion of esophageal cancer survivors displayed clinically significant anxiety or depression, which were primarily explained by their perceptions of esophageal cancer. Similarly, Traeger et al. (2009) explored whether IPs were related to emotional well-being in post-treatment prostate cancer patients. The sample included 214 men within 18 months of completing treatment for early stage prostate cancer. A moderate but significant correlation was shown between IP and emotional well-being. Jorgensen et al.'s (2009) study examined IP and psychological adjustment (distress and quality of life) among women who had survived breast cancer and attended a rehabilitation course. Three groups of breast cancer survivors were included in the study. Two groups attended a 1-week rehabilitation course, and the third group did not get any intervention. Findings from the study showed that IP explained 26% of the variance in global quality of life at baseline. No difference was noted in change of IP and the level of psychological adjustment observed between the three groups of survivors between baseline and at six months follow-up (Jorgensen et al., 2009). McCorry (2013) examined the extent to which IP and coping strategies among women with breast cancer explained PD relative to demographic and illness-related variables at diagnosis and at 6 months post-diagnosis. Results revealed that certain aspects of IP and positive coping were good predictors of lower PD. Similarly, Corter et al. (2013) found that among women

undergoing adjuvant endocrine therapy for breast cancer, all IP (except personal control) were significantly correlated with fear of recurrence. Hirsch et al. (2009) investigated how thyroid cancer patients perceived their illness correlated with several other variables (i.e., age, sex, education, stage of disease, time since diagnosis, time since last treatment, evidence of recurrence). Among those demographics, only level of education was significantly correlated with patients' IP. No significant correlation was found between age and IP. Hirsch et al. (2009) found a negative correlation between time elapsed since last treatment and IP. The literature supported the notion that IP play a major role in the PD (McCorry, 2013; Traeger et al., 2009).

Literature has been limited on studies among gynecologic populations. Bean et al. (2007) investigated ethnic differences in IP, self-efficacy, and diabetes self-care. Three ethnic groups were included: Europeans, South Asians, and Pacific Islanders. Pacific Islanders had elevated scores on three IP subscales (consequences, identity, and emotional representations) compared to the other groups. Similarly, Kim et al. (2012) explored racial/ethnic differences in IP in minority patients undergoing hemodialysis. One hundred sixty-one patients with end stage renal disease were included in this study. Racial/ethnic groups included were African Americans, Hispanics, Filipinos, and Koreans. Korean participants had higher emotional disturbance than other racial groups, whereas African-American participants had higher negative perceptions of personal interventions or medical treatments controlling their disease. Results from Bean et al. (2007) and Kim et al. (2012) indicated that patients from different racial/ethnic backgrounds may perceive their diseases differently. Similarly, results from the current

study also found that the non-White group perceived less consequence from their illness, indicating that there was a difference in IP based on race/ethnicity.

Furthermore, the current study found that the older participants reported lower IP, but Hirsh et al. (2009) found no correlation between age and IP. This difference could be due to the cancer type of the study sample. In terms of the relationship between IP and time since treatment, the findings were similar in this current study and Hirsch et al.'s (2009) study. This may indicate that longer intervals since treatment completion result in patients who are more likely to view illness as having a less severe effect on individuals. There is also the fact that the older group was now past child bearing and rearing years which would represent a significant threat for younger women.

Fear of Cancer Recurrence across Race/Ethnicity, Survivorship Status, and Age Groups

Results from this current study showed that the mean score for FCR was lower for non-Whites compared to Whites, suggesting that non-White participants reported lower worry or concern that the cancer might come back. FCR score was slightly higher among the younger age group than the older age group. Additionally, early survivors were found to have a higher FCR mean score than long-term survivors indicating that less time since treatment completion is associated with higher FCR.

Other studies have indicated that cancer survivors repeatedly experience FCR. Among women undergoing adjuvant endocrine therapy for breast cancer, Corter et al. (2013) found no significant difference in FCR between younger and older participants ($t = 1.56$, $df = 148$, $p = .12$). Liu et al. (2011) followed newly diagnosed breast cancer

patients and their FCR, conducting interviews at 4-6 weeks, 6 months, and 2 years after surgical treatment. In their study, FCR was measured using Concern About Recurrence Scale (CARS). At 2-year follow-up, 29% of participants reported moderate to high levels of FCR. Younger age and elevated anxiety were consistently associated with higher FCR. Older age at diagnosis predicted reduced FCR at 2-year follow-up in this study (Liu et al., 2011). No difference was seen in FCR based on the race ($p = .71$).

Petzel et al. (2012) evaluated the significance of FCR among patients treated with surgery for pancreatic and periampullary neoplasms. A clinically significant level of FCR was significantly associated with high levels of anxiety and depression ($P < 0.001$). FCR inventory was used to assess FCR. A high total FCR score on univariate analysis included non-White ethnicity ($P = 0.012$), young age ($P < 0.001$), and short time elapsed since pancreatectomy ($P < 0.001$) (Petzel et al., 2012).

Ziner et al. (2012) also examined FCR among breast cancer survivors. For their study, age 18-45 was included in the younger group and age 55-70 was included in the older group; the sample consisted of individuals at 3-8 years post-cancer diagnosis; and ages 46-54 were left out to test for differences between groups. Results revealed that younger women experienced more FCR than older women.

Kornblith et al. (2007) also found that younger breast and endometrial cancer survivors scored more poorly on FCR. Results from the current study were consistent with previous research, indicating that FCR score was higher among young age groups (Kornblith et al., 2007; Petzel et al., 2012; Ziner et al., 2012). In the study by Kornblith et

al. (2007), breast cancer survivors scored poorer on FCR than did endometrial cancer survivors. More research on FCR among gynecologic cancer survivors is needed. Although the current study revealed lower FCR among non-Whites, Petzel et al. (2012) found that non-Whites had a higher FCR; conversely, Liu et al. (2011) found no difference in FCR based on race. While not supported by findings from this study, it is possible that the difference in FCR could be due to participants' cancer type.

AIM 2, RESEARCH QUESTION 1: RELATIONSHIP BETWEEN PD, FCR AND IP WITH AGE AND SURVIVORSHIP DURATION WITHIN EACH RACIAL/ETHNIC GROUP

An overall negative correlation was noted between PD, FCR, and IP with age and survivorship duration among both Whites and non-Whites in the current study, indicating that young survivors and those with less disease-free years have more PD, FCR and IP. Although a negative correlation was noted between PD with age and survivorship duration among both Whites and non-Whites, the correlation was only significant for Whites. Age, however, resulted in a strong correlation with FCR and IP among both Whites and non-Whites indicating that age is a determining factor for FCR and IP for both White and non-White cancer survivors. The results also indicated that the number of disease-free years (survivorship duration) is an important determining factor for PD, FCR and IP among White participants, but for non-White participants, the number of disease-free years only affected their IP and it had no significant impact on PD or FCR.

Few studies have investigated the relationship between PD, IP, and FCR; however, these variables have been studied independently among various other cancer types. PD has been found to be lower among African Americans than Whites when

studying cancer survivors of breast, colorectal, and prostate cancers (Deimling, 2006). These findings were consistent with the results from Schootman et al. (2010), in which PD was more prevalent among Whites than African American cancer survivors. Schootman et al. (2010) used data from the 2005-2007 National Health Interview Survey (NHIS) to examine the racial disparities among various types of cancer survivors (bladder, breast, cervical, uterine, ovarian, colorectal, lung, lymphoma, melanoma, prostate, thyroid, and other). Unfortunately, PD differences between cancer types were not reported by Schootman et al. (2010).

Hoffman et al. (2009) examined PD among long-term survivors of adult-onset cancer and found that found that race was not correlated with PD. Hoffman et al. (2009) study respondents were also identified from the 2002-2006 NHIS, and cancer types were similar to Schootman et al.'s (2010) study. It is unclear why the findings were different between Hoffman et al. (2009) and Schootman et al. (2010). Dempster et al. (2011) reported that esophageal cancer survivors' IP explained the majority of variance in anxiety and depression experienced by participants. Additionally, FCR was found to be correlated with high levels of anxiety and depression when patients were examined following surgery for pancreatic cancer (Petzel et al., 2012).

The results from the current study demonstrated a lower PD among the older age group than the younger age group. Similarly, Brant (2011) found that higher distress was predicted by younger age. Although survivorship duration showed a significant correlation with PD, FCR, and IP among Whites, survivorship duration in non-Whites was only significantly correlated with IP. However, Hoffman et al. (2009) found no

association between number of years since cancer diagnosis and PD. This is similar to the findings by Hodgkinson et al. (2007) where number of years since diagnosis was not related to distress among long-term gynecologic cancer survivors. The difference in these findings could be attributed to differences in study samples.

Like the current study, Hirsch et al. (2009) found a negative correlation between time elapsed since prior treatment and IP—indicating that as survivorship duration increases, IP decreases. However, the correlation between IP and survivorship duration was significant for non-Whites in the current study. Additionally, older participants reported lower IP in the current study, but Hirsh (2009) found no correlation between age and IP. This difference could be due to the cancer type of the sample. Corter et al. (2013) found that among women undergoing adjuvant endocrine therapy for breast cancer, all aspects of IPs (except personal control) were significantly correlated with FCR. Bean et al. (2007) and Kim et al. (2012) indicated that patients from different racial/ethnic backgrounds may perceive their diseases differently. Similarly, the results from the current study found that non-White participants perceived less consequences resulting from their illnesses.

Other studies have confirmed that IP is correlated with PD (Dempster et al., 2011; Jorgensen et al., 2009; Traeger et al., 2009) and correlated to FCR among other types of cancer patients and survivors (Corter et al., 2013). Bean et al. (2007) examined ethnic difference in IP and diabetes self-care and found that, when comparing Europeans, Asians, and Pacific Islanders scores on three IP subscales (consequences, identity and emotional representations), scores higher for Pacific Islanders.

There are similarities and differences in the relationship between PD, FCR, and IP with age and survivorship duration between other research and the current study. Findings anomalies may result from difference in the sample based on cancer type and race/ethnicity, which indicate a need for further study of these variables among gynecologic cancers survivors.

AIM 2, RESEARCH QUESTION 2: DIFFERENCE IN PD, IP, AND FCR ACROSS AGE GROUPS, SURVIVORSHIP STATUS, AND RACIAL/ETHNIC GROUPS

The current study revealed a significant difference in PD ($t = 2.898$, $p < .05$), IP, ($t = 4.866$, $p < .05$), and FCR ($t = 2.234$, $p < .05$) between younger and older age groups; younger age groups had more PD, IP, and FCR than older age groups. No significant difference in PD and IP was noted between Whites and non-Whites. However, a marginally significant difference was noted in the FCR between Whites and non-Whites ($H = 3.408$, $p = .065$), with Whites having a greater FCR. The results of this current study also suggest that there is a significant difference in PD, FCR, and IP experienced by early versus long-term survivors or based on the survivorship status—with long-term survivors showing a lower PD, FCR, and IP.

Brant (2011) found that higher distress was predicted by younger age. This was consistent with Hoffman et al. (2009). Schootman et al. (2010) also showed that PD was different between race/ethnicity, and PD was found more prevalent among Whites than African American survivors. In contrast, Hoffman et al. (2009) found no difference in PD among survivors across race. Although the current study revealed a significant difference

in PD between early versus long-term survivors, Hodgkinson et al. (2007) did not find any difference based on the number of years since diagnosis.

Liu et al. (2011) found that younger age was consistently associated with higher FCR, suggesting that FCR differs based on age and is consistent with the findings from the current study. However, Corter et al. (2013) found no significant difference in FCR between younger and older participants. The current study found a marginally significant difference in FCR between Whites and non-Whites. However, Liu et al. (2011) found no difference in FCR based on race.

The current study revealed a significant difference in IP between younger and older age groups and early versus long-term survivors but no significant difference between Whites and non-Whites. As previously mentioned, few researchers have examined IP in the context of gynecologic cancer survivorship.

AIM 2, RESEARCH QUESTION 3: DO ILLNESS PERCEPTION, FEAR OF CANCER RECURRENCE, AGE, AND SURVIVORSHIP DURATION PREDICT PSYCHOLOGICAL DISTRESS ACROSS RACE/ETHNICITY AMONG GYNECOLOGIC CANCER SURVIVORS?

Results from this study revealed that for White participants, IP and survivorship duration were the best predictors of PD. But for non-White participants, IP alone was the best predictor for PD. Other studies have supported IP being a predictor for PD (Corter et al., 2013; Dempster et al., 2011; Jorgensen et al., 2009; McCorry, 2013; Traeger et al., 2009). However, no consensus exists on whether PD experienced by cancer survivors differs based on race. Schootman et al. (2010) found that PD was more prevalent among Whites than African American survivors, but Hoffman et al. (2009) found that race was

not associated with PD among survivors. Although Yanez et al. (2013) found some association between time since treatment and PD, other researchers found no association between number of years since cancer diagnosis and PD (Hodgkinson et al., 2007; Hoffman et al., 2009). This difference in the result could be due to the type of cancer observed in the study sample.

DISCUSSION OF FINDINGS WITHIN THE CONTEXT OF THE CONCEPTUAL FRAMEWORK

Meleis et al.'s (2000) transition theory was used to understand whether women's IP and FCR, in combination with select demographic variables, were related to PD during the survivorship phase. The major concepts of Meleis' middle range theory are: a) types of transitions; b) properties of transition experiences; c) transition conditions (facilitators and inhibitors); d) process indicators; e) patterns of response (outcome indicators or response); and f) nursing therapeutics. For the purpose of this study, three concepts from the framework were examined: a) type of transition, b) transition conditions, and c) patterns of response. In this study, *the type of transition* was cancer survivorship; *the transition conditions* were demographics, diagnoses, disease-free interval since treatment completion, IP, and FCR; and *the pattern of response* was PD. Results from this study revealed that the pattern of response (PD) during survivorship (type of transition) was negatively correlated with transition conditions (FCR, IP, age, and survivorship duration) among both Whites and non-Whites. For the White participants, the transition conditions (IP and survivorship) were the best predictors of the pattern of response (PD). But for non-White participants, transition condition (IP) was the best predictor of the pattern of response (PD).

LIMITATIONS OF THE STUDY

The sample in this study had an over-representation of ovarian cancer survivors and women who were Caucasian and spoke English. These sample characteristics limited the generalizability of the results to non-Caucasian and non-English speaking cancer survivors. Less common gynecologic cancers (e.g., vulvar, vaginal) were not included in this study; therefore, results cannot be generalized to survivors of less common gynecologic malignancies. In this study, the subjects self-identified themselves with their race, diagnoses and number of disease-free years. Therefore, self-selection bias is a limitation in this study. Further, this study was a cross-sectional survey, which did not allow for any conclusions about PD over time. Self-report bias is another limitation of this study.

IMPLICATIONS FOR PRACTICE, RESEARCH, AND EDUCATION

Since psychosocial care has been considered as an important aspect of quality cancer care for cancer patients by the Institute of Medicine, integration of psychosocial care into the routine care of cancer patients has now been mandated (NCCN, 2009). As increasing numbers of advance practice nurses (APN) participate in the care of cancer patients and survivors, a better understanding of PD and related variables can assist with the development of interventions to address PD experienced by gynecologic cancer survivors.

Evaluation of IP and its relation to PD among gynecologic cancer survivors has been limited, and cross-study comparisons are thus difficult. Future research among gynecologic cancer survivors using a direct data collection rather than online survey is

recommended to control participation based on age, diagnosis, and ethnicity. Although a direct data collection approach may be costly and time consuming, but it could improve generalizability of the findings.

Nurses play a vital role in the screening for PD among cancer patients and survivors. Nurses require knowledge and skills to perform their assessments. Additionally, communication is an important factor that is needed by nurses for appropriate screening, communication with clinicians, and to direct patients to appropriate services. It is therefore important to incorporate these aspects in nursing training to better assist cancer survivors who already have PD and screen patients who are at-risk for distress.

CONCLUSIONS AND IMPLICATIONS FOR NURSING

Several conclusions may be drawn from study findings. The overall conclusion is that gynecologic cancer survivors' experience PD and that FCR and IP play a role in the PD experienced by survivors. These findings are closely aligned with those of other researchers who have studied these concepts in survivors with other forms of cancer. Further, results indicate that non-Whites may experience PD differently from Whites. However, this finding should be viewed with caution because of the small number of non-White participants in this study. It may also be concluded that younger cancer survivors have more PD, FCR, and IP than older cancer survivors. Additionally, the results indicate that IP, FCR, and PD are elevated among early survivors than long-term survivor. Oncology nurses and Advanced Practice Nurses can validate that PD is an ongoing concern for gynecologic cancer survivors and refer them to appropriate services.

Appendix A: Study Flyer

Volunteers Needed!

Relationship of illness perception and fear of cancer recurrence to psychological distress among gynecologic cancer survivors

You are invited to participate in the above named study that will be conducted by Annamma (Anna) Sam, a doctoral student at the University of Texas Medical Branch at Galveston, Texas.

The purpose of this study is to explore the relationship between illness perception, fear of cancer recurrence and psychological distress among gynecologic cancer survivors. If you are a survivor of a uterine/endometrial cancer, ovarian cancer or cervical cancer and have been cancer free for at least 2 years since treatment completion, you are invited to participate in this study.

If you are eligible to participate, you will be asked to complete an online survey in English which will take approximately 25 minutes to complete. Participation is strictly voluntary and confidential. The survey link is:
https://www.surveymonkey.com/s/FDZ59DN

For more information, please contact the Principal Investigator:
Annamma (Anna) Sam, RN, MSN, WHNP at avsam@utmb.edu or 832-755-1223.

Appendix B: Facebook Invitation

If you are a survivor of a uterine/endometrial cancer, ovarian cancer or cervical cancer and have been cancer free for at least 2 years since treatment completion, you may be eligible to participate in a study to evaluate psychological distress among survivors.

If you are interested in participating, you will need to complete an online survey in English which will take approximately 25 minutes to complete. Participation is strictly voluntary and confidential. For more information, please contact the Principal Investigator: Annamma (Anna) Sam, RN, MSN, WHNP at avsam@utmb.edu or 832-755-1223.

The survey link is: **https://www.surveymonkey.com/s/FDZ59DN**

Appendix C: Survey Introductory Page

Welcome

My name is Annamma Sam, RN, MSN, WHNP. I am a doctoral student at the University of Texas Medical Branch in Galveston, Texas and I'm conducting this study as a part of the requirements for my degree. The title of my study is "**Relationship of illness perception and fear of cancer recurrence to psychological distress among gynecologic cancer survivors**". Psychological distress and fear of cancer returning are often described by many cancer survivors. How a person view their cancer experience can affect them emotionally. I hope to learn how one perceives his or her illness and the fear of cancer returning may play a role in psychological distress. The purpose of this study is to understand how illness perception and fear of cancer returning relates to psychological distress among women who are survivors of gynecologic cancer. Your answers will be completely anonymous.

This survey **will take about 25 minutes to complete.** To determine your eligibility for participation in the study you will be asked to answer four screening questions. If you are not eligible to participate, you will automatically exit the survey. If you are eligible to participate, you will be taken to the survey which will have four questionnaires to complete. You may stop answering the questions at any time if you feel uncomfortable. You may withdraw from the study any time before you complete the questionnaires and submit the survey. Once you have submitted your answers, there is no way to identify your answers and therefore after submission, we will be unable to remove your answers from the study.

If you have any questions about the study, concerns, or complaints before, during, or after the research please contact Annamma Sam at (832) 755-1223 or **avsam@utmb.edu** or my Supervising Professor Dr. Alice Hill at (409) 772-8251 or **ahill@utmb.edu**. You may also contact the Intuitional Review Board Office at (409) 266-9475 if you have any questions regarding your rights as a subject participating in this research study.

I have read the description of the study, and I have decided to participate in the research project described here. I understand that I may refuse to answer any (or all) of the questions. By answering the questions, I'm providing authorization to use my information for the study purposes. The authorization continues until the end of the research.

THANK YOU FOR YOUR PARTICIPATION!!

Appendix D: Screening Questions

The following questions are to confirm your eligibility for this study.

1. Do you have a history of a gynecologic cancer?

   ☐ Yes
   ☐ No

2. Have you been cancer free for 2 years or more?

   ☐ Yes
   ☐ No

3. Have you ever had a non-gynecologic cancer?

   ☐ Yes
   ☐ No

4. Are you 21 years or older?

   ☐ Yes
   ☐ No

Appendix E: Demographic Questionnaire

1. What is your Cancer Diagnosis?

    - ☐ Uterine or Endometrial Cancer
    - ☐ Ovarian Cancer
    - ☐ Cervical Cancer
    - ☐ Other (please specify) _____

2. How many years you been disease free since treatment completion for cancer? _____

3. What is your current age in years? _____

4. What is your race?

    - ☐ Non- Hispanic White
    - ☐ Hispanic White
    - ☐ African American/Black
    - ☐ Hispanic
    - ☐ Asian
    - ☐ Other (please specify) _____

Appendix F: Fear of Recurrence/Relapse Scale

Following statements reflect fear of cancer recurrence. In thinking about the past week, please indicate how much you agree or disagree with each statement. Choose one answer.

Statement	Strongly Agree	Agree	Not Certain	Disagree	Strongly Disagree
Because cancer is unpredictable, I feel I cannot plan for the future.	1	2	3	4	5
I will probably have a relapse (recurrence) in the next 5 years.	1	2	3	4	5
My fear of having my cancer getting worse gets in the way of my enjoying life.	1	2	3	4	5
I am afraid of my cancer coming back.	1	2	3	4	5
I am certain that I have been cured of cancer.	1	2	3	4	5

Appendix G: The Brief Illness Perception Questionnaire

The following questions are designed to help us understand how you feel about your cancer diagnosis. Please choose the number that best corresponds to your views about your cancer.

How much does your illness affect your life?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No affect at all										Severely affects my life

How long do you think your illness will continue?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
A very short time										Forever

How much control do you feel you have over your illness?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Absolutely no control										Extreme amount of control

How much do you think your treatment helped your illness?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Not at all										Extremely helpful

How much do you experience symptoms from your illness?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No symptoms at all										Many severe symptoms

How concerned are you about your illness?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Not at all concerned										Extremely concerned

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
Don't understand at all										Understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10
Not at all affected emotionally										Extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused the cancer.

The most important causes for me:-

1. _____
2. _____
3. _____

Appendix H: The Impact of Events Scale

Below is a list of comments made by people after stressful life events. Using the following scale, please indicate how often the following statements about your cancer were true for you during the past 7 days**.**

	Not at all	**Rarely**	**Sometimes**	**Often**
1. I thought about it when I didn't mean to.	0	1	3	5
2. I avoided letting myself get upset when I thought about it or was reminded about it.	0	1	3	5
3. I tried to remove it from memory.	0	1	3	5
4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came to my mind.	0	1	3	5
5. I had waves of strong feelings about it.	0	1	3	5
6. I had dreams about it.	0	1	3	5
7. I stayed away from reminders about it.	0	1	3	5
8. I felt as it hadn’t happened or was unreal.	0	1	3	5
9. I tried not to talk about it.	0	1	3	5
10. Pictures about it popped into my mind.	0	1	3	5
11. Other things kept making me think about it.	0	1	3	5
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	3	5
13. I tried not to think about it.	0	1	3	5
14. Any reminder brought back feelings about it.	0	1	3	5
15. My feelings about it were kind of numb.	0	1	3	5

References

Abeloff, M. D., Armitage J. O., Lichter A. S., & Niederhuber, J. E. (2000). *Clinical Oncology* (2nd ed.). New York, NY: Churchill Livingstone.

American Cancer Society. (2006). *Cancer facts and figures 2006*. Retrieved March 22, 2013, from http://www.cancer.org/downloads/STT/

American Cancer Society. (2012). *Cancer treatment and survivorship facts & figures 2012-2013.* Atlanta, GA: American Cancer Society.

Antoni, M. H., Lutgendorf, S. K., Cole, S. W., Dhabhar, F. S., Sephton, S. E., McDonald, P. G., Stefanek, M., & Sood, A. K. (2006). The influence of biobehavioural factors on tumor biology: Pathways and mechanisms. *Nature Reviews Cancer*, *6*, 240–248.

Armes, J. (2009). Patient's supportive care needs beyond the end of cancer treatment: A prospective, longitudinal survey. *Journal of Clinical Oncology, 27,* 6172-6178.

Aziz, N. M. (2002). Cancer survivorship research: Challenge and opportunity. *The Journal of Nutrition, 132,* 3494-3503.

Aziz, N. M. (2007). Cancer survivorship research: State of knowledge, challenges and opportunities. *Acta Oncologica, 46,* 417-432.

Baker, F., Denniston, M., Smith, T., & West, M. M. (2005). Adult cancer survivors: How are they faring? *Cancer, 104,* 2565-2576.

Bean, D., Cundy, T., & Petrie, K. J. (2010). Ethnic differences in illness perceptions, self-efficacy and diabetes care. *Psychology and Health, 22,* 787-811.

Bloom, J. R. (2002). Surviving and thriving? *Psycho-Oncology, 11*, 89–92.

Bloom, J. R., Petersen , D. M., & Kang, S. H. (2007). Multi-dimensional quality of life among long-term (5+ years) adult cancer survivors. *Psycho-oncology*, *16*, 691–706.

Bloom, J. R., Stewart, S. L., Chang, S., & Banks, P. J. (2004). Then and now: Quality of life of young breast cancer survivors. *Psycho-Oncology, 13*, 147–160.

Bowman, K. F. (2003). Appraisal of the cancer experience by older long-term survivors. *Psycho-Oncology, 12*, 226-238.

Bradley, S., Rose, S., Lutgendorf, S., Costanzo, E., & Anderson, B. (2006). Quality of life and mental health in cervical and endometrial cancer survivors. *Gynecologic Oncology, 100*, 479–486.

Brant, J. M. (2011). Symptom trajectories in posttreatment cancer survivors. *Cancer Nursing, 34*, 67-77.

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research, 60*, 631-637.

Broadbent, E., Donkin, L., & Stroh, J.C. (2011). Illness and treatment perceptions are associated with adherence to medications, diet, and exercise in Diabetic patients. *Diabetes Care, 34*, 338-340.

Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M., & Ramirez, A. (2005). Depression and anxiety in women with early breast cancer: Five year observational cohort study. *British Medical Journal, 330*, 702–705.

Burkett, V. S., & Cleeland, C. S. (2007). Symptom burden in cancer survivorship. *Journal of Cancer Survivorship, 1*, 67–75.

Cain, E. N., Kohorn, E. I., & Quinlan, D. M. (1983). Psychosocial reactions to the diagnosis of gynecologic cancer. *Obstetrics and Gynecology, 62,* 635–641.

Carlson, L. E., & Bultz, B. D. (2003). Benefits of psychosocial oncology care: improved quality of life and medical cost offset. *Health and Quality of Life Outcomes, 1*, 1-9.

Cavelti, M., Contin, G., Beck, E.-M., Kvrgic, S., Kossowsky, J., Stieglitz, R.-D., & Vauth, R. (2012). Validation of the illness perception questionnaire for Schizophrenia in a German speaking sample of outpatients with outpatients with chronic schizophrenia. *Psychopathology*, *45*, 259-269.

CDC (2004). Cancer survivorship—United States, 1971–2001. *MMWR Morbidity, Mortality Weekly Report, 53,* 526–529.

Chick, N., & Meleis, A. I. (1986). Transitions: A nursing concern. In P. L. Chinn (Ed.), *Nursing research methodology: Issues and implementation* (pp. 237-257). Rockville, MD: Aspen.

Cimprich, B., Ronis, D., & Martinez-Ramos, G. (2002). Age at diagnosis and quality of life in breast cancer survivors. *Cancer Practice, 10,* 85–93.

Coffey, S.F. (2006). Screening for PTSD in motor vehicle accident survivors using the PSS-SR and IES. *Journal of Traumatic Stress, 19,* 119-128.

Corcoran, K., & Fischer, J. (1994). *Measures for clinical practice—A source book* (3rd ed.). New York, NY: The Free Press.

Corter, A. L., Findlay, M., Broom, R., Porter, D., & Petrie, K. J. (2013). Beliefs about medicine and illness are associated with fear of cancer recurrence in women

taking adjuvant endocrine therapy for breast cancer. *British Journal of Health Psychology, 18*, 168-181.

Costanzo, E. S., Lutgendorf, S. K., Bradley, S. L., Rose, S. L., & Anderson, B. (2005). Cancer attributions, distress, and health practices among gynecologic cancer survivors. *Psychosomatic Medicine*, *67*, 972-980.

Dahl, L., Wittrup, I., Vaeggemose, U., Petersen, L. K., Blaakaer, J. (2013). Life after gynecologic cancer: A review of patient's quality of life, needs, and preferences in regard to follow-up. *International Journal of Gynecologic Cancer*, *23*, 227-233.

Deimling, G. T. (2006). Coping among older adult, long-term cancer survivors, *Psycho-Oncology, 15*, 143-159.

Dempster, M., McCorry, N. K., Brennan, E., Donnelly, M., Murray, L. J., & Johnston, B. T. (2011). Illness perceptions among cancer survivor-dyads are related to psychological distress among esophageal cancer survivors. *Journal of Psychosomatic Research, 70*, 432-439.

Dempster, M., McCorry, N. K., Brennan, E., Donnelly, M., Murray, L. J., & Johnston, B. T. (2012). Psychological distress among survivors of esophageal cancer: the role of illness cognition and coping. *Diseases of the Esophagus, 22*, 222-227.

DeVellis, R. F. (2012). *Scale development: Theory and applications* (3rd ed.). Thousand Oaks, CA: Sage

Drapeau, A., Marchand, A., & Beaulieu-Prévost, D. (2012). Epidemiology of psychological distress. In Luciano Labate (Ed.), *Mental illnesses*—

Understanding, prediction and control (pp. 105-134). Retrieved March 22, 2013 from http://www.intechopen.com/books/mental-illnesses-understanding-prediction-and-control

Edwards, B. K., Howe, H. L., Ries, L. A. G., Thun, M. J., Rosenberg, H. M., Yancik, R., Wingo, P. A., Jemal, A., & Feigal, E. G. (2002). Annual report to the nation on the status of cancer, 1973–1999: Featuring implications of age and aging on U.S. cancer burden. *Cancer*, *94*, 2766–2792.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analysis using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41*, 1149-1160.

Fawzy, F.I. (1999). Psychosocial interventions for patients with cancer: What works and what doesn't. *European Journal of Cancer, 35*, 1559-64.

Ferlay, J., Bray, F., Pisani, P., & Parkin, D. M. (2004). GLOBOCAN 2002: Cancer incidence, mortality and prevalence worldwide. *IARC CancerBase* No. 5, version 2.0. Lyon, France: IARCPress.

Ferrell, B., Smith, S. L., Cullinane, C. A ., & Melancon, C. (2003). Psychological well-being and quality of life in ovarian cancer survivors. *Cancer*, *98*, 1061-1071.

Ganz, P. A., Desmond, K. A., Leedham, B., Rowland, J. H., Meyerowitz, B. E., & Belin, T. R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. *Journal of National Cancer Institute, 94*, 39–49.

Goncalves, V. (2010). Long-term quality of life in gynecologic cancer survivors. *Current Opinion in Obstetrics and Gynecology, 22*, 30-35.

Greenberg, D. B., Kornblith, A. B., Herndon, J. E., Zuckerman, E., Schiffer, C. A., Weiss, R., Mayer, R. J., Wolchok, S. M., & Holland, J. C. (1997). Quality of life of adult leukemia survivors treated on clinical trials of the Cancer and Leukemia Group B from 1971-1988: Predictors for later psychological distress. *Cancer*, *80*, 1936-1944.

Groenvold, M., Petersen, M. A., Idler, E., Bjorner, J. B., Fayers, P. M., & Mouridsen, H. T. (2007). Psychological distress and fatigue predicted recurrence and survival in primary breast cancer patients. *Breast Cancer Research and Treatment, 105*, 209–219.

Grov, K. L., Fossa, S. D., & Dahl, A. A. (2011). Short-term and long-term elderly cancer survivors: A population-based comparative and controlled study of morbidity, psychosocial situation, and lifestyle. *European Journal of Oncology Nursing*, *15*, 213-220.

Hewitt, M., Greenfield, S., & Stovall, E. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: The National Academy Press.

Hill, J. M., Kornblith, A. B., Jones, D., Freeman, A., Holland, J. F., Glicksman, A. S., Boyett, J. M., Lenherr, B., Brecher, M. L., Dubowy, R., Kung, F., Maurer, H., & Holland, J. C. (1998). A comparative study of the long-term psychosocial functioning of childhood acute leukemia survivors treated by intrathecal methotrexate with and without cranial radiation. *Cancer*, *82*, 208-218.

Hirsch, D., Ginat, M., Levy, S., Benbassat, C., Weinstein, R., Tsvetov, G., Singer, J., Shraga-Slutzky, I., Grozinski-Glasberg, S., Mansiterski, Y., Shimon, I., & Reicher-Atir, R. (2009). Illness perception in patients with differentiated epithelial cell thyroid cancer. *Thyroid*, *19*, 459-465.

Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G. E., Stenlake, A., Hobbs, K. M., Brand, A., & Wain, G. (2007). Long-term survival from gynecologic cancer: Psychosocial outcomes: supportive care needs and positive outcomes. *Gynecology Oncology*, *104*, 381-389.

Hoffman, K. E., McCarthy, E. P., Recklitis, C. J., & Ng, A. K. (2009). Psychological distress in long-term survivors of adult-onset cancer. *Archives of Internal Medicine, 169*, 1274-1281.

Holland, J. C. (1999). NCCN practice guidelines for the management of psychosocial distress: National Comprehensive Cancer Network. *Oncology, 13*, 113-147.

Holland, J. C., & Alici, Y. (2010). Management of distress in cancer patients. *The Journal of Supportive Oncology*, *8*, 4-12.

Hong, Y. M. (2010). Impact of radical prostatectomy positive margins on fear of cancer recurrence: Results from CaPSURE. *Urologic Oncology: Seminars and Investigations, 28*, 268-273.

Horowitz, M., Wilner, M., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine, 41*, 209-218.

Horwitz, A.V. (2007). Distinguishing distress from disorder as psychological outcomes of stressful social arrangements. *Health, 11*, 273-289.

Howlader, N., Noone, A. M., Krapcho, M., Garshell, J., Neyman, N., Altekruse, S. F., Kosary, C. L., Yu, M., Ruhl, J., Tatalovich, Z., Cho, H., Mariotto, A., Lewis, D. R., Chen, H. S., Feuer, E. J., & Cronin, K. A. (Eds.) (2012). *SEER Cancer Statistics Review, 1975-2010*. National Cancer Institute: Bethesda, MD. Retrieved April 15, 2013 from http://seer.cancer.gov/csr/1975_2010/

Janz, N. K. (2011). Correlates of worry about recurrence in a multi-ethnic population-based sample of women with breast cancer. *Cancer, 117*, 1827–1836.

Jorgensen, I. L., Frederiksen, K., Boesen, E., Elsass, P., & Johansen, C. (2009). An exploratory study of associations between illness perceptions and adjustment and changes after psychosocial rehabilitation in survivors of breast cancer. *Acta Oncologica*, *48*, 1119-1127.

Khan, N. F., Rose, P. W., & Evans, J. (2012). Defining Cancer survivorship: a more transparent approach is needed. *Journal of Cancer Survivorship*, *6*, 33-36.

Kim, Y., Pavlish, C., Evangelista, L. S., Kopple, J. D., & Phillips, L. R. (2012). Racial/ethnic differences in illness perceptions in minority patients undergoing maintenance hemodialysis. *Nephrology Nursing Journal*, *39*, 39-49.

Kornblith, A. B. (1998). Psychosocial adaptation of cancer survivors. In J. Holland (Ed.), *Psycho-oncology* (pp. 223-254), New York, NY: Oxford University Press.

Kornblith, A. B., Powell, M., Regan, M. M., Bennett, S., Krasner, C., Moy, B., Younger, J., Goodman, A., Berkowitz, R., & Winer, E. (2007). Long-term psychosocial adjustment of older vs. younger survivors of breast and endometrial cancer. *Psycho-Oncology*, *16*, 895-903.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer.

Leventhal, H., Brissette, I., & Leventhal, E. (2003). The common-sense model of self-regulation of health and illness. In L. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behavior* (pp. 42-65). London, UK: Routledge.

Liu, Y., Perez, M., Schootman, M., Aft, R. L., Gilanders, W. E., & Jeffe, D. B. (2011). Correlates of fear of cancer recurrence in women with ductal carcinoma in-situ and early invasive breast cancer. *Breast Cancer Research and Treatment, 130,* 165-173.

Lockwood-Rayerman, S. (2006). Survivorship issues in ovarian cancer: A review. *Oncology Nursing Forum*, *33*, 553-562.

Lynch, B. M., Steginga, S. K., Hawkes, A. L., Pakenham, K. I., & Dunn, J. (2008). Describing and predicting psychological distress after colorectal cancer. *Cancer*, *112*, 1363-1370.

Mah, K., Bezjak, A., Loblaw, D. A., Gotowiec, A., & Devins, G. M. (2011). Do ongoing lifestyle disruptions differ across cancer types after the conclusion of cancer treatment? *Journal of Cancer Survivorship*, *5*, 18-26.

Matulonis, U. A., Kornblith, A., Lee, H., Bryan, J., Gibson, C., Wells, C., Lee, J., Sullivan, L., & Penson, R. (2008). Long-term adjustment of early-stage ovarian cancer survivors. *International Journal of Gynecological Cancer*, *18,* 1183-1193.

McCorry, N. K. (2013). Illness perception clusters at diagnosis predict psychological distress among women with breast cancer at 6 months post diagnosis. *Psycho-Oncology, 22*, 692-698.

Mehnert, A., Berg, P., Henrich, G ., & Herschbach, P. (2009). Fear of cancer progression and cancer-related intrusive cognitions in breast cancer survivors. *Psycho-Oncology, 18*, 1273–1280.

Mehta, S. S., Lubeck, D. P., Pasta, D. J., & Litwin, M. S. (2003). Fear of cancer recurrence in patients undergoing definitive treatment for prostate cancer: Results from CaPSURE. *Journal of Urology*, *170*, 1931-1933.

Meleis, A. I. (2000). Transition Theory. In A. M. Tomey & M. R. Alligood, *Nursing theorists and their work* (7th ed.) (pp. 416-433). St. Louis, MO: Mosby Elsevier.

Meyerowitz, B. E., Kurita, K., & D'Orazio, L. M. (2008). The psychological and emotional fallout of cancer and its treatment. *The Cancer Journal, 14*, 410-413.

Millar, K., Purshotham, A. D., McLatchie, E., George, D., & Murray, G. D. (2005). A 1-year prospective study of individual variation in distress and illness perceptions after treatment for breast cancer. *Journal of Psychosomatic Research, 58*, 335–342.

Mirowsky, J., & Ross, C. E. (2002). Selecting outcomes for the sociology of mental health: Issues of measurement and dimensionality. *Journal of Health and Social Behavior*, *43*, 152-170.

Mullan F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine, 313*, 270–273.

Nail, L. M. (2001). I'm coping as fast as I can: Psychosocial adjustment to cancer and cancer treatment. *Oncology Nursing Forum, 28*, 967-70.

National Cancer Institute (NCI). (2002). *Facing Forward Series: Life after cancer treatment.* Bethesda, MD: National Cancer Institute.

National Comprehensive Cancer Network (2009). *Distress Management Clinical Practice Guidelines in Oncology, version 1.* Retrieved September 16, 2013 from www.nccn.org/professionals/physician_gls/f_guidelines.asp#supportive.

Norton, T. R. (2004). Prevalence and predictors of psychological distress among women with ovarian cancer. *Journal of Clinical Oncology, 22*, 919-926.

Nunnally, J.C., & Bernstein, I. H. (1978). *Psychometric theory* (3rd ed.). New York, NY: McGraw-Hill.

Petzel, M., Parker, N., Valentine, A., Simard, S., Nogueras-Gonzalez, G., Lee, J., Pisters, P., Vauthey, J.-N., Fleming, J., & Katz, M. (2012). Fear of cancer recurrence after curative pancreatectomy: A cross-sectional study in survivors of pancreatic and perimapullary tumors. *Annals of Surgical Oncology, 19*, 4078-4084.

Phillips, K. M., McGinty, H. L., Gonzalez, B. D., Jim, H. S., Small, B. J., Minton, S., Andrykowski, M. A., & Jacobsen, P. B. (2012). Factors associated with breast cancer worry 3 years after completion of adjuvant treatment. *Psycho-Oncology, 22*, 936-939.

Rees, G., Fry, A., Cull, A., & Sutton, S. (2004). Illness perceptions and distress in women at increased risk of breast cancer. *Psychology and Health, 19*, 749-765.

Ridner, S. H. (2004). Psychological distress: Concept analysis. *Journal of Advanced Nursing, 45,* 536-545.

Roberts, C. S., Rossetti, K., Cone, D., & Cavanagh, D. (1992). Psychosocial impact of gynecologic cancer: A descriptive study. *Journal of Psychosocial Oncology, 10,* 99–109.

Scharloo, M., Baatenburg de Jong, R., Langeveld, T., van Velzen-Verkaik, E., Doorn-op den Akker, M., & Kaptein, A. (2005). Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer. *Head Neck, 27,* 857–63.

Schootman, M., Deshpande, A., Pruitt, S., Aft, R., & Jeffe, D. (2010). National estimates of racial disparities in health status and behavioral risk factors among long-term cancer survivors and non-cancer controls. *Cancer Causes and Control, 21,* 1387-1395.

Schumacher, K. L., & Meleis, A. I. (1994). Transitions: a central concept in nursing. *Image Journal of Nursing Scholarship, 26,* 119-127.

Siegel, R., DeSantis, C., Virgo, K., Stein, K., Marlotto, A., Smith, T., Cooper, D., Gansler, T., Lerro, C., Fedewa, S., Lin, C., Leach, C., Cannady, R., Cho, H., Scoppa, S., Hachey, M., Kirch, R., Jemal, A., & Ward, E. (2012). Cancer Treatment and Survivorship Statistics, 2012. *CA: A Cancer Journal for Clinicians, 62:* 220-241.

Traeger, L., Penedo, F., Gonzalez, J., Dahn, J., Lechner, S., Schneiderman, Antoni, M. (2009). Illness perceptions and emotional well-being in men treated for localized prostate cancer. *Journal of Psychosomatic Research, 67, 389-397.*

Urbaniec, O. V., Collins, K., Denson, L. A., & Whitford, H. S. (2011). Gynecologic cancer survivors: assessment of psychological needs and unmet supportive care needs. *Journal of Psychosocial Oncology, 29*, 534-551.

Valdivieso, M., Kujawa, A. M., Jones, T., & Baker, L. H. (2012). Cancer survivors in the United States: A review of literature and call to action. *International Journal of Medical Sciences, 9*, 163-173.

Vickberg, S. M. (2003). The Concerns About Recurrence Scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *Annals of Behavioral Medicine, 25*, 16–24.

Wenzel, L. B. (2002). Resilience, reflection, and residual stress in ovarian cancer survivorship: A gynecologic oncology group study. *Psycho-Oncology, 11*, 142-153.

Wheaton, B. (2007). The twain meets: Distress, disorder and the continuing conundrum of categories. *Health, 11*, 303-319.

Yanez, B., Garcia, S., Victorson, D., & Salsman, J. (2013). Distress among young adult cancer survivors: A cohort study. *Supportive Care in Cancer, 21*, 2403-2408.

Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site, *Psycho-Oncology, 10*, 9–28.

Zeng, Y. C., Li, D., & Loke, A. Y. (2011). Life after cervical cancer: Quality of life among Chinese women. *Nursing and Health Sciences, 13*, 296-302.

Ziner, K. W., Sledge, G. W., Bell, C. J., John, S., Miller, K. D., & Champion, V. L. (2012). Predicting fear of breast cancer recurrence and self-efficacy in survivors by age. *Oncology Nursing Forum, 39,* 287- 295.

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