THE LIVED EXPERIENCES OF WOMEN DIAGNOSED
WITH STAGE II OR GREATER GYNECOLOGICAL CANCER

by

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ABSTRACT

STACEY M. MEYERS
THE LIVED EXPERIENCES OF WOMEN DIAGNOSED WITH STAGE II OR GREATER
GYNECOLOGICAL CANCER
Under the direction of DR. HELEN HODGES

Women diagnosed with late stage gynecological cancer encounter unique physical and psychosocial stressors compared to other cancer diagnoses, including poor survival rates. The existing body of literature focuses on identifying individual stressors or symptoms, studies one type of gynecological cancer, or quantifies symptom experiences. This interpretive phenomenological research study focused on the lived experiences of women diagnosed with stage II or greater gynecological cancer and it explored the individual’s perspective related to quality of life, personal perceptions of cancer-related stigma, and the health-illness transition.

Meleis’ transitions theory and Roy’s adaptation model provided the conceptual framework for this study. Ten women diagnosed with stage II or greater gynecological cancer, primarily from the Midwestern United States, were included in this study. Interpretive phenomenological approach and Saldana’s (2013) processes of coding were used to guide data analysis from participant interviews. Five primary themes and 12 subthemes emerged from within the data describing
The Existential Experience of Time, Awareness of Loss, Navigating New Waters, Sustaining Faith, and Moving Forward.

This research promotes understanding of the personal perception and impact of the diagnosis of cancer, adaptation to the environmental stressor of cancer, and discovering meaning in the cancer experience and its impact on survivorship. This research highlighted the importance of communication by the health care provider throughout the patient’s cancer journey, and clarified the critical importance and impact of the nurse’s relationship with the patient during this process. Other implications for practice include improving knowledge of the physical and emotional changes these women experience throughout this process, in addition to recognizing the losses the women encounter and the modes of adaptation they utilize.

Within this study, women diagnosed with late stage gynecological cancer provided rich, thick descriptions of the lived experience of an advanced gynecological cancer diagnosis. The unique physical and psychosocial symptoms these women experience are intertwined and influence patients’ perception of time and quality of life. Findings illuminated the significance of the health-illness transition and the concepts of adaptation and stigmatization that occur in women with advanced stage gynecological cancer and this study can provide the framework for future research in these areas.
CHAPTER 1
INTRODUCTION TO THE STUDY

Women diagnosed with gynecological cancer encounter unique physical and psychosocial stressors compared to other cancer diagnoses (Beesley et al., 2008; Guenther, Stiles, & Champion, 2012; Holt, Hansen, & Mogensen, 2014; Howell, Fitch, & Deane, 2003; Jefferies & Clifford, 2011; Phillips-Salimi & Andrykowski, 2013; Steele & Fitch, 2008). These stressors include cancer-related stigma, late stage diagnosis, distinct experiences of isolation and loneliness, intense decisions related to treatment, and extensive treatment regimens which may result in the loss of reproductive capabilities (Abbott-Anderson & Kwekkeboom, 2011; Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011; Guenther et al., 2012; Howell et al., 2003; Jefferies & Clifford, 2011; Kissane et al., 2013; Manne et al., 2014; Sevil, Ertem, Kavlak, & Coban, 2006; Shepherd & Gerend, 2014). Furthermore, survival rates are poor for women who are diagnosed with gynecological cancer, specifically late stage ovarian, endometrial, and cervical cancer (American Cancer Society, 2018; Beesley et al., 2010; Guenther et al., 2012; Howell et al., 2003; Jefferies & Clifford, 2011; Manne et al., 2014).
The existing body of literature focuses on identifying individual physical and emotional stressors (Abbott-Anderson & Kwekkeboom, 2011; Steele & Fitch, 2008), the quantification of the severity of physical and emotional stressors (Manne et al., 2014; Steele & Fitch, 2008), the examination of one type of gynecological cancer (Howell et al., 2003; Jefferies & Clifford, 2011), or the inclusion of women of all ages (Holt et al., 2014; Jefferies & Clifford, 2011; Sevil et al., 2006). A collective study of these physical and psychosocial stressors does not exist. Furthermore, the available studies are primarily quantitative or systematic reviews, while the minimal number of qualitative studies focus on one specific type of gynecological cancer despite identified stressors being common across the gynecological oncology spectrum.

Further qualitative studies are needed to understand how the overall impact of these physical and psychosocial stressors can influence patients’ quality of life and life experiences following an advanced stage gynecological cancer diagnosis. Additionally, a study is warranted to examine if these life experiences are shared among women with advanced stage gynecological cancer type, specifically ovarian, uterine cervix (cervical), and uterine corpus (endometrial) cancers with poorer prognoses. Finally, it is important to explore the impact of gynecological cancer diagnoses in women (specifically ages 18 to 39 years old), as it has significant impact on reproductive capabilities and life expectancy, in comparison to women age 40 or older. After the age of 40, a female has only a 5% chance of conceiving, which maturationally limits reproductive capabilities and therefore, loss of
reproductive ability may not directly relate to the cancer diagnosis and treatment (American Society for Reproductive Medicine, 2012).

Identification of the Phenomenon of Interest

In the year 2018, approximately 878,980 women will be newly diagnosed with cancer (American Cancer Society, 2018). While gynecological cancer diagnoses will account for only 110,070 of these new cases, or approximately 12.5%, these cancer types will be among the leading causes of cancer deaths for women (American Cancer Society, 2018). This estimate is based on data collected annually by the American Cancer Society from the previous year and updated each year.

Gynecological cancers are defined as cancer of the female genitalia or reproductive system (American Cancer Society, 2018). The five types of gynecological cancer are ovarian, uterine cervix (cervical), uterine corpus (endometrial), vaginal, and vulvar (American Cancer Society, 2018).

Despite the smaller number of diagnoses of gynecological cancer primary tumor sites compared to other primary tumor site diagnoses like breast cancer, gynecological cancers will account for nearly as many deaths in 2018 as breast cancer, the second leading cause of cancer deaths in females (American Cancer Society, 2018). In 2018, approximately 41,400 women will die from breast cancer, while it is estimated that 32,120 women will die from all gynecological cancers combined (American Cancer Society, 2018). The cause of this disparity is two-fold. Gynecological cancers, specifically ovarian, uterine cervix (cervical), and uterine corpus (endometrial) are often diagnosed in later stages and have worse prognoses
compared to breast cancer (American Cancer Society, 2018; Howell et al., 2003; Vandborg et al., 2011). Furthermore, the disparity in the number of women diagnosed with advanced stage gynecological cancer as compared to breast cancer can make it a difficult population to study. There are nearly two times more women diagnosed with breast cancer each year and those women often have better long-term prognoses and survival rates compared to women diagnosed with late stage gynecological cancers (American Cancer Society, 2018; Beesley et al., 2010; Guenther et al., 2012; Howell et al., 2003).

The American Cancer Society (2014) simplified staging across all primary tumors sites in all cancer types by identifying disease states as localized, regional, and distant stages. Localized staging was defined as no spreading of disease to lymph nodes or other locations outside the primary tissue or organ affected (American Cancer Society, 2014). Regional staging was defined as cancer that has spread (metastasized) to lymph nodes or tissue within direct proximity of the primary cancer site (American Cancer Society, 2014). Distant staging was identified as cancer that has metastasized to remote lymph nodes, tissue, and organs from the primary cancer site (American Cancer Society, 2014). Based on these definitions, gynecological cancers identified as stage II or greater would be classified as regional or distant staging of disease (American Cancer Society, 2014).

While the mortality rate of women diagnosed with all stages of breast cancer has shown a significant decline since 1989, the mortality rate of ovarian cancer declined by only 2.8% in women under 65 and 1.7% in women 65 and older, from
2006 to 2010 (American Cancer Society, 2014). Mortality rates of young women (less than 50 years old as defined by the American Cancer Society, 2014) diagnosed with uterine cervix (cervical) cancer have remained stable in recent years while mortality rates in women diagnosed with uterine corpus (endometrial) cancer are increasing by 1.5% per year (American Cancer Society, 2014). Likewise, the five-year survival rate, women who live five years past initial diagnosis, is 90% for women diagnosed with any stage of breast cancer and 83% for 10-year survival rate (American Cancer Society, 2014). In comparison, the five-year and 10-year survival rates for ovarian cancer patients across all stages are 44% and 35% respectively. The five-year survival rate for uterine cervix (cervical) cancer patients across all stages is 68% and the five-year survival rates across the spectrum of stages is 82% for uterine corpus (endometrial) (American Cancer Society, 2014). Each of the five-year survival rates for ovarian, cervical, and endometrial cancer is significantly less than that of breast cancer, with ovarian cancer having the lowest survival rate.

Health-Related Stigma

In addition to unique physical and psychosocial stressors and poor mortality rates, women diagnosed with gynecological cancer are at risk for health-related stigmas, specifically cancer-related stigma. Health-related stigma is defined as the “social disqualification of individuals and groups who have particular health problems” (Cataldo et al., 2011; Shepherd & Gerend, 2014, p. 95). Stigmas may result from personal or societal perceptions and interpretations of a cancer diagnosis (Cataldo et al., 2011; Kissane et al, 2013; Shepherd & Gerend, 2014). This
health-related stigma may be perceived by the individual based on his/her internalized feelings of shame associated with a medical diagnosis, or may be enacted by members of society when actual discrimination occurs (Lebel et al., 2013; Shepherd & Gerend, 2014). Cataldo et al. (2011) expanded the definition of health-related stigma to include “a personal experience characterized by exclusion, rejection, blame, or devaluation that results from anticipation of an adverse judgment . . . judgment based on an enduring feature of identity conferred by a health issue” (p. 46).

The process of stigmatization is comprised of four steps (Shepherd & Gerend, 2014). The first step is an individual being labeled as distinctive. The second step occurs when this distinction is categorized as undesirable and can lead to stereotyping. The third step results in the distinct individuals being separated from others in society. In the last step, those individuals who are labeled as distinctive are “excluded, rejected, devalued, and as a result lose status and experience discrimination” (Shepherd & Gerend, 2014, p. 95).

Sociologist Erving Goffman maintained there were two types of stigma, enacted and felt, in his theory of social stigma (Goffman, 1963; Lebel et al., 2013; Lebel & Devins, 2008). Enacted stigma is an actual experience of discrimination, while felt stigma is the “fear of being discriminated against and the internalized sense of inferiority and shame” (Goffman, 1963; Lebel et al., 2013; Lebel & Devins, 2008, p. 717). Shepherd and Gerend (2014) further expanded the two types of stigma delineated by Goffman (1963) to four types of stigma. The four types of
stigma outlined by Shepherd and Gerend (2014) are public stigma, self-stigma, stigma by association, and structured stigma.

Shepherd & Gerend (2014) noted public stigma stems from the stigmatization of individuals with certain conditions due to public perception of the condition. These authors posited public stigma could occur through reactive or deliberative processes. Reactive stigma is an emotional process, while deliberative stigma is a cognitive process (Shepherd & Gerend, 2014).

Stigma by association results from individuals being linked to those who are stigmatized (Shepherd & Gerend, 2014). Structural stigmas are stigmas that are perpetuated by societal views. Lastly, self-stigma embraces the concept of felt stigma outlined by Goffman (1963). Self-stigma is the self-perception of stigma directly related to feelings of fear and shame (Shepherd & Gerend, 2014).

Self-stigmatization often stems from thoughts of self-blame (Shepherd & Gerend, 2014). The concept of self-blame can be categorized as behavioral or characterological (Else-Quest, LoConte, Schiller, & Hyde, 2009). Behavioral self-blame is associated with guilt or shame related to one's behavior, while characterological self-blame is related to direct shame and negative emotions about oneself (Else-Quest et al., 2009).

Cancer-Related Stigma

The notion of self-blame and self-stigmatization become particularly relevant when exploring the concept of cancer-related stigma. Attribution theory has been used to enhance understanding of cancer-related stigma and self-blame (Else-Quest
Attribution theory examines how an individual determines the cause of specific events; in this case what caused the development of cancer (Idemudia & Matamela, 2012; Lebel & Devins, 2008). Attribution theory contends conditions that are caused by voluntary actions, such as lung cancer and smoking, can lead to stigmatization by society (Lebel & Devins, 2008). Likewise, conditions that are perceived as uncontrollable by the individual result in sympathetic reactions by society (Lebel & Devins, 2008).

Building on the concept of control delineated in the attribution theory, stigmatization in cancer patients often occurs when the cancer diagnosis can be related to an individual’s “onset-controllable” behavior; that is, the patient had a choice in participating in the behavior that caused the cancer (Cataldo et al., 2011; Else-Quest et al., 2009; Idemudia & Matamela, 2012; Kissane et al., 2013; Lebel et al., 2013; Lebel & Devins, 2008, p. 718; Shepherd & Gerend, 2014). Self-blame is strongly correlated with smoking in lung cancer (Chapple, Ziebland, & McPherson, 2004; Else-Quest et al., 2009; Gonzalez & Jacobsen, 2012; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008), tobacco and alcohol use in head and neck cancer (Kissane et al., 2013; Lebel et al., 2013), and the exposure to the human papilloma virus in cervical cancer (Daley et al., 2010; Kahn et al, 2007; Shepherd & Gerend, 2014; Waller, Marlow, & Wardle, 2007). The concept of self-blame will be examined further, in addition to the concept of cancer-related stigmas and gynecological cancer.
The outcomes associated with cancer stigmatization are significant. Cancer-related stigma outcomes can be divided into three categories. These categories are personally driven outcomes (Idemudia & Matamela, 2012; Lebel & Devins, 2008), societally driven outcomes (Idemudia & Matamela, 2012; Kromm, Smith, & Singer, 2007; Lebel et al., 2013), and healthcare driven outcomes (Kahn et al., 2007; Waller et al., 2007). For the purpose of this study, personally and societally driven outcomes of cancer-related stigma will be primarily explored.

The first classification of outcomes is categorized as personally driven outcomes. This classification is comprised of outcomes associated with stigmatization within the direct control of the patient (Chapple et al., 2004; Daley et al., 2010; Else-Quest et al., 2009; Gonzalez & Jacobsen, 2012; Idemudia & Matamela, 2012; Kahn et al., 2007; Kissane et al., 2013; Lebel et al., 2013; Lebel & Devins, 2008; LoConte et al., 2008; Shepherd & Gerend, 2014; Waller et al., 2007). Such outcomes include feelings of guilt and shame, self-blame, distress, and associated symptoms of depression, anxiety, and poor quality of life (Else-Quest et al., 2009; Idemudia & Matamela, 2012; Lebel et al., 2013; Lebel & Devins, 2008; LoConte et al., 2008). As previously discussed, the concept of self-blame is prevalent among persons who perceive their actions have caused the development of their cancer and promotes self-stigmatization (Chapple et al., 2004; Daley et al., 2010; Else-Quest et al., 2009; Gonzalez & Jacobsen, 2012; Idemudia & Matamela, 2012; Kahn et al., 2007; Kissane et al., 2013; Lebel & Devins, 2008; Lebel et al., 2013; LoConte et al., 2008; Shepherd & Gerend, 2014; Waller et al., 2007). Self-blame can have a significant impact on
individuals diagnosed with cancer, including associated symptoms, such as depression and anxiety, and increased distress (Else-Quest et al., 2009; Idemudia & Matamela, 2012; Lebel et al., 2013).

Holland, Anderson, et al. (2010) defined distress in cancer as a “multivariate, unpleasant, emotional experience of psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (p. 450). Distress occurs along a continuum from normal feelings associated with vulnerability, sadness, and fear to psychological and spiritual symptoms that interfere with daily function (Holland, Anderson, et al., 2010). This distress can lead to significant associated symptoms.

As distress increases so does the risk for associated symptoms, including anxiety, depression, and decreased quality of life (Cataldo et al., 2011; Lebel et al., 2013). In several studies, it was determined that an increase in feelings of self-blame and distress directly correlated with an increase in anxiety and depressive symptoms (Cataldo et al., 2011; Else-Quest et al., 2009; Gonzalez & Jacobsen, 2012; Lebel et al., 2013; LoConte et al., 2008; Phelen et al., 2013). These symptoms can directly impact a person’s quality of life and can lead to poor patient outcomes (Cataldo et al., 2012; Chambers et al., 2012).

Other symptoms closely associated with distress and self-blame are related to the concepts of guilt and shame. A belief that an individual had caused his/her cancer was connected to higher levels of guilt and shame (Kissane et al., 2013; LoConte et al., 2008). Guilt was defined by LoConte et al. (2008) as “self-conscious
negative feelings about one’s behavior or behavioral self-blame” (p. 172). Shame, on the other hand, is associated with negative feelings about oneself (LoConte et al., 2008). These feelings of guilt and shame are significant as they may impact an individual’s social, marital, and family relationships (Kissane et al., 2013).

The final component of personally driven outcomes is the subjective knowledge of the disease (Kahn et al., 2007; Shepherd & Gerend, 2014; Waller et al., 2007). This phenomenon has been well researched with individuals who have been diagnosed with human papillomavirus, a sexually transmitted infection, and the associated risk for developing cervical cancer (Daley et al., 2010; Kahn et al., 2007; Shepherd & Gerend, 2014; Waller et al., 2007). Feelings of fear, self-blame, shame, guilt, and distress were increased following a diagnosis of cervical cancer if the woman had previous knowledge about the risks of human papillomavirus and how it was contracted (Daley et al., 2010; Kahn et al., 2007; Shepherd & Gerend, 2014; Waller et al., 2007). Likewise, even if there was no previous knowledge of the associated risks of human papillomavirus, once knowledge was obtained related to how the disease was contracted, women felt increased levels of shame, guilt, and self-blame (Daley et al., 2010; Kahn et al., 2007; Shepherd & Gerend, 2014; Waller et al., 2007).

One positive outcome associated with the personal knowledge of cervical cancer and its primary cause was the “normalization effect” (Kahn et al., 2007; Waller et al., 2007, p. 157). The human papillomavirus is the most commonly contracted sexually transmitted infection (Kahn et al., 2007; Waller et al., 2007).
Therefore, when health care providers were able to outline the prevalence of the
disease and its common occurrence among the public, women were less likely to
exhibit negative feelings and behaviors (Kahn et al., 2007; Waller et al., 2007).

Societally driven outcomes comprise the second category of cancer-related
stigma. As outlined by Goffman (1963) and the attribution theory, health-related
stigma is both personally and societally driven. The societally driven outcomes of
cancer stigmatization are judgment related to physical deformities (Arunachalam,
Thirumoorthy, Devi, & Thennarasu, 2011; Bonanno & Esmaeli, 2012; Goffman,
1963; Kissane et al., 2013; Lebel et al., 2013), lack of acceptance by the individual’s
culture (Doumit, Huijer, Kelley, Saghir, & Nassar, 2010; Idemudia & Matamela, 2012;
McCaffery et al., 2003; Tsuchiya, Horn, & Ingham 2012), and media representation
of cancer (Kromm, Smith, & Singer, 2007; Kwan et al., 2010; Smith, 2007;
Williamson, Jones, & Hocken, 2011).

The impact of cancer-related stigma associated with physical deformities is
largely driven by public perception of the physical deformity. Deformities, whether
temporary or permanent, result from treatment measures for cancer (Arunachalam
et al., 2011; Bonanno & Esmaeli, 2012; Kissane et al., 2013; Lebel et al., 2013).
Physical deformities, such as those associated with the surgical removal of a tumor
in head and neck cancer, can result in decreased socialization (Bonanno & Esmaeli,
2012; Kissane et al., 2013; Lebel et al., 2013). This lack of socialization can occur
due to felt or enacted stigma (Goffman, 1963; Lebel et al., 2013). Furthermore,
Arunachalam et al. (2011) concluded that not only did disfigurement associated
with cancer treatment lead to decreased quality of life, the impact of disfigurement on females was significantly more distressing than for their male counterparts.

Cultural perspectives of the identified illness also largely impact health-related stigmas. Idemudia & Matamela (2012) determined patients have more negative outcomes related to their illness if the cause of the illness is undesirably viewed by the culture of the patient. This conclusion coincides with the study findings by Doumit et al. (2010). Doumit et al. (2010) found coping strategies for Lebanese women diagnosed with breast cancer were impacted by the negative stigma of cancer maintained by the Lebanese culture.

The final component of societally driven outcomes of cancer stigma is the media’s representation of cancer. How a concept, such as cancer, is depicted in the media will largely influence the public’s opinion of said concept (Kromm et al., 2007; Kwan et al., 2010; Smith, 2007; Williamson et al., 2011). Therefore, if the media depicts positive messages associated with cancer, like the strength of cancer survivors, cancer stigmatization subsequently decreases (Kromm et al., 2007). Likewise, if the media associates negative messages with cancer patients and survivors, cancer stigmatization increases (Kromm et al., 2007).

For example, in a study conducted by Kwan et al. (2010), the researchers examined how messaging related to cervical cancer and its link to the human papillomavirus impacted perceptions of the disease. Study participants were primed with one of three messages pertaining to sexual promiscuity and high-risk human papillomavirus infection (Kwan et al., 2010). When later asked about the
sexual stigma associated with human papillomavirus, participants in the group primed with the most de-stigmatizing message were more likely to have neutral responses than the other two groups in the study (Kwan et al., 2010).

Smith (2007) and Williamson et al. (2011) also explored how media message presentation could impact public perception of diseases. Smith (2007) determined the societal appraisal of a disease was influenced by how print media formatted a health message related to the disease, such as messages about cancer and the correlation to a sexually transmitted disease. Williamson et al. (2011) also advocated for a strong relationship between health care providers and journalists in order to provide accurate information to the public in order to decrease the associated stigmatization of cancer.

Positive representation of cancer in the media is just one way to improve the negative outcomes associated with cancer-related stigma. Decreasing the acute and long-term psychosocial effects correlated with cancer diagnoses and treatments can lead to improved patient outcomes and quality of life (Holland, 2001; Holland, Kelley, & Weinberger, 2010). This can be achieved by integrating psychosocial services into cancer care in order to reduce distress and enhance patient well-being (Holland, 2001; Holland, Kelley, et al., 2010).

The National Comprehensive Cancer Network (2018) designed a clinical guideline pertaining to survivorship. The guideline advocated the use of psychosocial screening measures in cancer survivors as a way to reduce distress and improve outcomes for these individuals (National Comprehensive Cancer
The goal of this guideline, and the previous studies mentioned pertaining to psychosocial services, is to enhance the overall well-being of cancer survivors (Holland, 2001; Holland, Kelley, et al., 2010; National Comprehensive Cancer Network, 2018).

Purpose of the Study

This interpretive phenomenological research study focused on the lived experiences of women diagnosed with stage II or greater gynecological cancer, specifically ovarian, uterine, and endometrial cancer, and it explored the individual’s perspective related to quality of life, personal perceptions of cancer-related stigma, and the health-illness transition.

Research Questions

This research study examined the lived experiences of women diagnosed with stage II or greater gynecological cancer and was guided by the following research questions:

1. What are the lived experiences of women diagnosed with stage II or greater gynecological cancer?
2. What are the health-illness transitions that occur in women diagnosed with stage II or greater gynecological cancer?
3. What are the perceptions of women of the stigma associated with a diagnosis of gynecological cancer?
4. What daily behaviors of women are influenced by the environmental stressor of the cancer diagnosis?
Conceptual Framework

Meleis’ transitions theory and Roy’s adaptation model provided the conceptual framework for this study. These theories provided a conceptual framework for understanding the lived experiences of women diagnosed with stage II or greater gynecological cancer. This study primarily focused on the health-illness transition in women diagnosed with stage II or greater gynecological cancer and how the environmental stressor of the cancer diagnosis may have influenced the women’s behavior.

Meleis’ Transitions Theory

Following a conceptual analysis of transitions, Meleis et al. (2000) developed the middle-range theory of transitions. Meleis identified four major transitions an individual may experience related to health care; these transitions are developmental, situational, health-illness, and organizational (Meleis, 2010; Meleis et al., 2000; Schumacher & Meleis, 1994). Through the conceptual analysis of transitions, Meleis determined transitions impact not only patients in health care, but also health care providers (Meleis et al., 2000; Schumacher & Meleis, 1994). Moreover, Meleis et al. (2000) found transitions are “both a result of and result in change in lives, health, relationships, and environments” (p. 13).

During the development of the transitions theory, it was essential to clearly define the concept of transitions. Chick and Meleis (2010) defined transition as the change in life “phase, condition, or status” (p. 25). It was proposed transitions occur when an individual interacts with his/her environment. The transition process is
influenced by the individual’s interpretation of the transitional event and how he/she responds to said event. Chick and Meleis (2010) proposed the transition process could be utilized in health care research to understand changes in health, changes in health-seeking behavior, and changes in health care utilization.

Meleis et al. (2000) were able to build on the conceptual analysis of transitions outlined in previous studies (Chick & Meleis, 2010; Schumacher & Meleis, 1994). The theoretical framework of the transitions theory was influenced by four major components. The four components were the nature of the transition, the facilitators and inhibitors of transition conditions, the patterns of response, and nursing therapeutics (Meleis et al., 2000). Each of these components was comprised of multiple facets.

The nature of the transition is the first component of the transitions theory (Meleis et al., 2000). Meleis and her colleagues (2000) emphasized transitions are defined as the types, patterns, and properties of the transition. The three factors that comprise the nature of transitions will be examined more in depth.

The four types of transitions are developmental, situational, health-illness, and organizational (Meleis, 2010; Meleis et al., 2000; Schumacher & Meleis, 1994). Developmental transitions are changes that occur related to the various stages of the life cycle, such as pregnancy and menopause (Hottar-Pollara, 2010; Im & Meleis, 1999; Marnocha, Bergstrom, & Dempsey, 2011; Meleis, 2010; Schumacher & Meleis, 1994). Situational transitions occur as a direct result of circumstances surrounding an individual (Meleis, 2010; Schumacher & Meleis, 1994). Situational transitions
can be varying and may include such things as immigration (Hilfinger Messias, 2010), hospital discharge (Weiss et al., 2007), and nursing education and knowledge (Brennan & McSherry, 2010). Health-illness transitions explore the impact of an illness on an individual and his/her family (Beaudet & Ducharme, 2013; Meleis, 2010; Schumacher & Meleis, 1994). Finally, organizational transitions are social, political, economic, or structural changes in the health care environment (Meleis, 2010; Reid Ponte, Gross, Winer, Connaughton, & Hassinger, 2010; Schumacher & Meleis, 1994).

The nature of transitions is also comprised of the patterns and the properties of the transition (Chick & Meleis, 2010; Meleis et al., 2000). Meleis et al. (2000) defined the pattern of transitions as one transition occurring or multiple transitions occurring at one time. Transitions may occur sequentially or simultaneously and may be related or unrelated (Meleis et al., 2000). The properties of the transition experience include awareness, engagement, change and difference, time span, and critical points and events (Chick & Meleis, 2010; Meleis et al., 2000).

The second component of transitions theory is the conditions that facilitate or inhibit the transition process (Meleis et al., 2000). Environmental, community or society, or personal conditions may help or hinder the process of a healthy transition for the individual (Meleis et al., 2000; Schumacher & Meleis, 1994). Personal influences on transitions include subjective meaning of the transition, cultural beliefs and attitudes, socioeconomic status, and individual preparation and knowledge of the transition (Meleis et al., 2000; Schumacher & Meleis, 1994).
Community resources and societal conditions may also influence an individual’s transitional experiences (Meleis et al., 2000).

Patterns of response are the third component of transitions theory (Meleis et al., 2000). Patterns of response were divided into process indicators and outcome indicators. Process indicators were identified as the ability to feel connected, interact, develop confidence and coping, and the location and situation of the individual. Outcome indicators were recognized as the mastery of new skills to help in the transitional process and the development of “fluid yet integrative identity” (Meleis et al., 2000, pp. 25-26). A fluid integrative identity refers to the individual’s ability to maintain his/her personal identity while adapting to identity changes that correlate with the transition process (Meleis et al., 2000).

The fourth and final component of the transitions theory is nursing therapeutics (Meleis et al., 2000). Nursing therapeutics can be defined as the ways nurses help patients, families, and communities manage the transition process (Meleis, 2010; Meleis et al., 2000). Three models were identified as representative of nursing therapeutics in the transition process (Meleis, 2010). The three models include transitional care model (Meleis, 2010; Naylor & Van Cleave, 2010), role supplementation (Meleis, 2010; Swendsen, Meleis, & Jones, 2010), and debriefing (Meleis, 2010; O’Connor & Jeavons, 2010).

Meleis et al. (2000) proposed the middle-range transitions theory as a framework to guide nursing care during complex and vulnerable periods for patients and families. By utilizing this theoretical framework in care, nurses can
promote healthy transitions for patients and families (Meleis, 2010; Meleis et al., 2000). The application of the transitions theory in practice has occurred in a variety of health care settings and situations, which is indicative of its ease of use in practice (Meleis, 2010).

Meleis’ transitions theory provided an important part of the conceptual framework for this study, specifically the health-illness transition experience of women diagnosed with stage II or greater gynecological cancer. For the purpose of this study, the health-illness transition pertains to the individual’s perspective of the transition from a well person to a person diagnosed with cancer (Meleis, 2010; Schumacher & Meleis, 1994). Understanding this transition process for women diagnosed with gynecological cancer is inherent in the purpose of the study.

Roy’s Adaptation Model

One additional complementary theoretical component for this study was identified and was utilized throughout the research process. The theory identified was one of two of the paradigmatic origins of Meleis’ transitions theory (Chick & Meleis, 2010). This theory is Roy’s adaptation model of stress and coping (Chick & Meleis, 2010).

Roy’s adaptation model was utilized to augment understanding and analyze the qualitative data collected throughout this study process. This model was used to understand the change in societal role identity of women diagnosed with gynecological cancer and explore the diagnostic effects on personal identity, family, and society during the health-illness transition. Roy’s adaptation model proposed
that a person is a biological, psychological, and sociological individual who is consistently interacting with his/her environment (Roy, 2009). Changes in the environment will subsequently influence the behavior of the individual. This environment is continually changing and requires the individual to adapt to the fluctuations within said environment. Individual adaptation must occur in order to manage environmental changes (Roy, 2009).

Adaptation takes place through two processes in the individual, the regulator and cognator subsystems (Meleis, 2012; Roy, 2009). The regulator subsystem is described as the basic type of adaptation that occurs through automatic neural, chemical, and endocrine responses to environmental stimuli (Meleis, 2012; Roy, 2009). The cognator subsystem is more complex, as it stores the information in order to assign meaning to the behavior (Meleis, 2012; Roy, 2009). The cognator subsystem is comprised of four cognitive-emotional channels, which are perceptual and information processing, learning, judgment, and emotion (Roy, 2009).

Adaptation must occur when the individual is exposed to internal or external stimuli (Roy, 2009). Should adaptation fail to occur in any of these four processes, maladaptation occurs (Roy, 2009). In order to prevent maladaptation from taking place, the individual has four modes of adaptation. These four modes of adaptation are physiologic-physical needs, self-concept-group identity, role function, and interdependence (DeSanto-Madeya & Fawcett, 2009). The regulator subsystem primarily relates to the physiological-physical adaptive mode whereas the cognator subsystem relates to all adaptive modes (Roy, 2009).
Each of these adaptive modes will be examined more in depth. The physiological-physical adaptive mode pertains to meeting the individual’s physiological needs, such as oxygenation and nutrition, in order to maintain the physical integrity of the individual (Roy, 2009). The self-concept-group identity results from the individual’s psychiatric and spiritual wellness, which then transforms into social group identity integration (Roy, 2009; Roy, 2011). The individual must integrate within the four group levels of family, organizations, communities, and global society (Roy, 2011). The focus of the role function mode is to determine one’s social relationship within the group to act in accordance with the needs of the group (Roy, 2009). Finally, the interdependence mode allows for support systems and relationships to occur (Roy, 2009). Despite the distinction of these four adaptive modes, the individual is viewed holistically throughout the model and this process (Dobratz, 2008).

The purpose of the four modes of adaptation is to assess the “adaptive human/group responses . . . to promote person and environment transformations, and ultimately promote health” (Dobratz, 2008, p. 255). Roy (2009) defined health as an “individual’s total well-being” (p. 3) and the process of becoming an integrated, whole person. It is during this interaction between the person, environment, and health that the role of the nurse develops. The nurse aids the individual when his/her adaptive modes are unable to cope with the stressor he/she is experiencing due to illness or threat of illness (Meleis, 2012). The
ultimate goal of nursing is to "promote adaptation in the four adaptive modes, contributing to the health, quality of life, and dying with dignity" (Roy, 2011, p. 346).

In her adaptation model, Roy (2009) proposed that nurses utilize a six-step process when interacting with nursing clients in order to promote overall well-being and health. These steps include the assessment of behavior, the assessment of the stimuli, development of a nursing diagnosis, goal setting, intervention, and evaluation (Roy, 2009). Through this process, it becomes essential to not only understand the stressor the patient is experiencing, but also his/her perception of the stressor. The stressor only has meaning based on the patient's associated value of the stressor (Dobratz, 2008). The nurse's primary goal throughout this process is to improve patient adaptation to stressors, minimize maladaptive responses, and promote health through enhanced environment and person interactions (Roy, 2009).

Understanding women's perceptions of stressors associated with a diagnosis of gynecological cancer was a major focus of this study. Likewise, the study explored the associated value of the stressors identified by individuals participating in the study, while investigating the change in societal role identity of women diagnosed with gynecological cancer during the health-illness transition. From this capacity, Roy's adaptation model improved understanding of the lived experiences of women diagnosed with gynecological cancer.
Significance of the Study

This study will expand the body of knowledge as it relates to the lived experiences of women diagnosed with gynecological cancer. Furthermore, it will increase understanding of how physical and psychosocial stressors influence patients’ quality-of-life and life experiences following a gynecological cancer diagnosis. Additionally, a study was warranted to examine if these life experiences are shared among women with advanced stage gynecological cancer diagnoses with poorer prognoses, specifically ovarian, uterine cervix (cervical), and uterine corpus (endometrial) cancers, while differentiating experiences of women diagnosed prior to the age of 40 and after the age of 40. Finally, it was important to explore the impact of reproductive cancer diagnoses in women ages 18 to 39, as it has a significant impact on reproductive capabilities and life expectancy.

By utilizing a conceptual framework comprised of Meleis’ transitions theory and Roy’s adaptation model, women’s experiences of being diagnosed with stage II or greater gynecological cancer was further understood. A comprehensive picture from diagnosis to survivorship was outlined. Through identification of the health-illness transition and cancer-related stigma in gynecological cancer, this study may provide the framework for future research in women’s health and cancer collectively. Likewise, by understanding the individual perspectives of women diagnosed with gynecological cancer, the study identified shared experiences of women with gynecological cancer.
Assumptions and Biases

Several assumptions and biases were addressed prior to the implementation of this study. The first was my assumption that because women diagnosed with gynecological cancer have unique physical and psychosocial stressors they must face compared to other cancer diagnoses, their life experiences will have similarities following diagnosis. For example, women may experience similar emotions like grief, anger, and depression. Likewise, because the prognosis for women diagnosed with later stage ovarian, endometrial, and cervical cancer is usually poor, they will have shared experiences post diagnosis that will impact their quality of life. I assumed the experiences of women, ages 18 to 40 years old, diagnosed with later stage gynecological cancer will have varying experiences from life experiences of women over 40 years old, primarily related to loss of reproductive abilities and shortened life span, as reported in previous literature. Likewise, I assumed that women will have societal role identity changes, due to the impact of changes in societal integration at the time of diagnosis.

Furthermore, the information shared by participants in this study is sensitive, and I assumed all participants are willing to divulge this sensitive information with me. Finally, by utilizing Meleis’ transition theory, Roy’s adaptation model, and the concept of cancer-related stigma, I assumed women diagnosed with gynecological cancer encountered at least one of these life experiences following their diagnosis. At this time, there are no biases that need to identified or addressed.
Definition of Terms

There are several terms that must be defined in relation to the research study. These terms included cancer staging, health-illness transitions, gynecological cancer, adaptation, stressor, and cancer-related stigma. Each of these terms will be examined below.

Gynecological Cancer

Gynecological cancers are defined as cancer of the female genitalia or reproductive system (American Cancer Society, 2018). The five types of gynecological cancer are ovarian, uterine cervix (cervical), uterine corpus (endometrial), vaginal, and vulvar (American Cancer Society, 2018). For the purpose of this study, ovarian, cervical, and endometrial cancer were primarily explored.

Cancer Staging

The American Cancer Society (2014) simplified staging by identifying disease states as localized, regional, and distant stages. Localized staging was defined as no spreading of disease to lymph nodes or other locations outside the primary tissue or organ affected (American Cancer Society, 2014). Regional staging was defined as cancer that has spread (metastasized) to lymph nodes or tissue within direct proximity of the primary cancer site (American Cancer Society, 2014). Distant staging was identified as cancer that has metastasized to remote lymph nodes, tissue, and organs from the primary cancer site (American Cancer Society, 2014). Based on these definitions, all gynecological cancers identified as stage II or greater
would be classified as regional or distant staging of disease (American Cancer Society, 2014).

Cancer-Related Stigma

Cataldo and colleagues’ (2011) expanded definition of health-related stigma was utilized to define cancer-related stigma for the purposes of this study. Cancer-related stigma is “a personal experience of exclusion, rejection, blame, or devaluation that results from anticipation of an adverse judgment . . . judgment based on an enduring feature of identity conferred by a health issue” (Cataldo et al., 2011, p. 46). In this study, the perceived judgment and stigma directly relates to the diagnosis of gynecological cancer.

Health-Illness Transition

For the purpose of this study, Chick and Meleis’ (2010) description of transition as the change in life “phase, condition, or status” (p. 25) was utilized as the definition of transition. Transitions occur when an individual interacts with his/her environment and changes result in the individual’s life, health, relationships, or situation (Chick & Meleis, 2010; Meleis et al., 2000). Two processes influence transitions: How the individual understands the transitional event and how the individual responds to that event (Chick & Meleis, 2010). Building on this description, the health-illness transition would be outlined as the individual’s perspective of the transition from a well person to a person diagnosed with cancer (Meleis, 2010; Schumacher & Meleis, 1994).
Adaptation and Stressor

Utilizing Roy's (2009) adaptation model, a definition of adaptation and stressor was identified. Roy proposed a person is a biological, psychological, and sociological individual that is consistently interacting with his/her environment. A change in the environment of the individual will cause stress and this environmental change will subsequently influence the behavior of the individual and cause the individual to adapt to their new environment. Therefore, for the purpose of this study, when a woman was diagnosed with the environmental stressor of cancer, said stressor would influence her behavior, and adaptation will occur.

Summary

This study expanded the body of knowledge as related to the lived experiences of women diagnosed with gynecological cancer. The purpose of this qualitative research study was to understand the overall impact of the unique physical and psychosocial stressors experienced by women diagnosed with stage II or greater gynecological cancer. Furthermore, this study examined if these life experiences were shared among women with advanced stage gynecological cancer diagnoses with poorer prognoses, specifically ovarian, uterine cervix (cervical), and uterine corpus (endometrial) cancers. Likewise, it was essential to understand the age at the time of diagnosis and the impact of reproductive cancer diagnoses in young women (specifically ages 18 to 40 years old), as it has a significant effect on reproductive capabilities and life expectancy.
Meleis’ transitions theory and Roy’s adaptation model provided the conceptual framework for this study. In addition, Roy’s adaptation model was used to examine and analyze the health-illness transition. By utilizing this multi-focused conceptual framework, a more comprehensive picture of women’s experiences of being diagnosed with stage II or greater gynecological cancer was revealed, in addition to improved understanding of survivorship.
CHAPTER 2

REVIEW OF RELATED LITERATURE

This chapter will provide a review of related literature. A literature review was completed using a systematic approach for inclusion and exclusion criteria. The themes identified throughout the literature search will be examined more in depth in this chapter. These themes provided the historical and experiential context for the current study. This chapter will also explore the conceptual framework chosen to guide this study and the interpretive phenomenological approach utilized in this study that will guide data collection and analysis. Finally, a synthesis of existing literature and inferences for the current study will be discussed in this chapter.

Context of the Study

The incidence of gynecological cancer in the American population is steadily increasing (American Cancer Society, 2018). Furthermore, consistent themes and shared experiences of women diagnosed with gynecological cancer were identified through the literature review. The historical and experiential context of this study will be explored further.
Historical

In 2018, it is estimated that 110,070 women will be newly diagnosed with gynecological cancer (American Cancer Society, 2018). This number has increased over the years, including nearly a 12% increase in the number of new gynecological cancer cases from 98,280 in 2015 to 110,070 in 2018 (American Cancer Society, 2015). Likewise, the number of estimated deaths has increased from 30,440 in 2015 to 32,120 in 2018, a growth of over 5.5% (American Cancer Society, 2018). In addition, gynecological cancer remains one of the leading causes of cancer deaths for women (American Cancer Society, 2018).

A systematic review of qualitative, quantitative, and mixed methods reviews related to gynecological cancer was conducted. Studies that examined the lived experiences of women diagnosed with breast cancer were also included due to the limited number of gynecological cancer articles that were available. These articles also identified shared experiences between breast and gynecological cancer. The literature search was completed using the CINAHL, OVID, ProQuest, PubMed, BioMed Central, and Cochrane databases. Literature published after 2007 was preferred, however articles published after 2003 were also included in the review due to the limited articles that were available. The primary search term for all databases was “gynecological cancer.” The terms “lived experiences,” “quality-of-life,” and “women” were also used to narrow the search results. The inclusion criteria were articles written in the English language, online full-text availability, international journal publications, primary focus in gynecological oncology, and
preference for qualitative research approach. The search results were narrowed based on the titles or abstracts of the references and the inclusion criteria.

Currently, there are very limited articles and dissertations available that collectively explored the lived experiences of women diagnosed with gynecological cancer that are not disease site, treatment, symptom, or culturally specific. For example, when examining the literature, two studies examined the lived experiences of Chinese and Zambian women diagnosed with cervical cancer, including the cultural contexts, implications, and stigmas associated with cervical cancer (Ding, Hu, & Hallberg, 2015; Maree & Kaila, 2014). One study explored the lived experiences of women diagnosed with ovarian cancer within a phenomenological approach (Guenther et al., 2012), while two studies examined the quality of life and the lived experiences of women diagnosed with ovarian cancer (Howell et al., 2003; Swenson, MacLeod, Williams, Miller, & Champion, 2003). Finally, one study explored the lived experience of aloneness identified by women diagnosed with vulvar cancer (Jefferies & Clifford, 2011).

Further exploration of the literature revealed the current body of knowledge focuses on the disease site, treatment methods, symptom identification or management, primary inclusion of older adult participants, or a primary focus on the physical or psychosocial components of the gynecological cancer. Each of these concepts and studies will be examined more in depth. The following will provide a summary of the literature currently available, while delineating the need for the proposed research study.
Throughout the literature review, studies of women’s lived experiences with site-specific gynecological cancer were identified. For example, two studies explored the lived experiences of women diagnosed with ovarian cancer, with one study specifically exploring concepts of survivorship and returning to work (Guenther, 2008; Kinney, 2006). Furthermore, a study conducted by Fieler (2007) investigated women’s thoughts related to the symptoms of ovarian cancer. While the primary focus of this study identified the symptoms women experienced pre-diagnosis, it also highlighted the impact of the healthcare provider-patient relationship. Finally, a study conducted by Levin (2013) found that physiological symptoms of menopause in young breast and gynecological cancer survivors led to increased symptoms of depression, cancer-specific stress, and stress related to body changes.

Several studies explored the treatment effects of gynecological cancer. For example one study aimed to understand the effects of gynecological surgical interventions on gender identity and the lived experiences of the individual as it relates to the surgical procedure (Elson, 2000). MacDonald’s (2003) research focused on the onset of early menopause and infertility in young adult cancer survivors. It is important to note this study did not focus specifically on gynecological cancer. Likewise, a study by McCallum (2013) explored how many gynecological cancer survivors have unmet sexual and psychosocial needs long-term related to treatment effects. Abbott-Anderson’s (2015) research also aimed to explore and identify the sexual effects related to gynecological cancer by developing the Sexual Concerns Questionnaire – Gynecological Cancer. A key finding of this
study identified a higher level of sexual concerns in younger, pre-menopausal women.

The physical and/or psychosocial effects of gynecological cancer and treatment were the primary focus of the following research studies. Sexuality and body image were explored in Caldwell’s (2003) mixed methods study of gynecological cancer. This study found that 100% of the participants interviewed reported their gynecological cancer negatively impacted intimate relationships and heightened participant emotions. Camperson (2009) also explored the emotional experiences of women diagnosed with gynecological cancer ages 28 to 67. The concept of resiliency was a primary focus of this study, while exploring the onset of depression symptoms following diagnosis. Likewise in a study by Rezk (2011) identifying the impact of gynecological cancer on quality of life, it was determined the spectrum of symptoms gynecological cancer survivors face negatively impact their overall quality of life. Finally, a study conducted by Chow (2013) recognized the impact of psychosocial educational interventions on sexual function, quality of life, and psychological outcomes in gynecological cancer survivors.

Experiential

When exploring the literature on women’s experiences with gynecological cancer, many themes were identified. The first theme was the unique physical and psychosocial stressors these women experience (Beeseley et al., 2008; Caldwell, 2003; Camperson, 2009; Chow, 2013; Fieler, 2007; Guenther et al., 2012; Holt et al., 2014; Howell et al., 2003; Jefferies & Clifford, 2011; Phillips-Salimi & Andrykowski, 2013; Rzek, 2011; Steele & Fitch, 2008). Cancer-related stigma, late stage diagnosis,
distinct experiences of isolation and loneliness, intense decisions related to
treatment, extensive treatment regimens, and loss of reproductive capabilities were
identified as primary stressors in this population (Abbott-Anderson, 2015; Abbott-
Anderson & Kwekkeboom, 2011; Cataldo et al., 2011; Guenther et al., 2012; Howell
et al., 2003; Jefferies & Clifford, 2011; Kissane et al., 2013; Levin, 2013; MacDonald,
2003; Manne et al., 2014; Sevil et al., 2006; Shepherd & Gerend, 2014). Poor
survival rates, specifically in late stage ovarian, endometrial, and cervical cancer,
were also recognized in this population (American Cancer Society, 2018; Beesley et
al., 2010; Guenther et al., 2012; Howell et al., 2003; Jefferies & Clifford, 2011; Manne
et al., 2014).

The existing body of literature focuses on identifying the physical and
emotional stressors (Abbott-Anderson & Kwekkeboom, 2011; Steele & Fitch, 2008)
and the quantification of the severity of physical and emotional stressors (Manne et
al., 2014; Steele & Fitch, 2008). Furthermore, the existing literature exams one type
of gynecological cancer (Howell et al., 2003; Jefferies & Clifford, 2011) or includes
women of all ages in the study sample (Holt et al., 2014; Jefferies & Clifford, 2011;
Sevil et al., 2006). It is important to understand how these experiences impact
young women differently and if any experiences are shared across the spectrum of
gynecological cancer.

Philosophical Underpinnings

A phenomenological approach was utilized to understand the lived
experiences of women following the diagnosis of stage II or greater gynecological
cancer. Heidegger's interpretive phenomenological research method was used as
the framework to guide this study. The results of this study provided evidence that identified shared lived experiences of women across the gynecological cancer spectrum and may guide future research in this area.

The method of interpretive phenomenology was chosen to guide this study, as it aims to understand the everyday experience of individuals (Benner, 1994; Draucker, 1999; Munhall, 2012; Polit & Beck, 2012). Phenomenology, by definition, is both a philosophy and methodological approach for research (Cohen, Kahn, & Steeves, 2000). It is also proposed that phenomenology allows the researcher to fully comprehend and understand the lived experiences of an individual (Dreyfus, 1991; Munhall, 2012; Saldaña, 2013).

Extending from Heidegger's original works and expansion from Dreyfus' (1991) study on interpretive phenomenology came Patricia Benner's (1994) method for utilizing interpretive phenomenology in nursing research (Mackey, 2005). Interpretation, as defined by Benner (1994), occurs through identifying paradigm cases and exemplars (Mackey, 2005). The paradigm case is created when the text is read and analyzed for complete understanding of the phenomenon (Benner, 1994; Mackey, 2005). From there, exemplars are utilized to provide and demonstrate themes and patterns within qualitative research (Benner, 1994; Mackey, 2005).

Qualitative health research, within the context of interpretive phenomenology, allows for scientific understanding of the lived experiences of individuals (Sandelowski, 2004). Likewise, the nursing profession can be further transformed through the understanding of the human perspective and experience
(Benner, 1994). This qualitative approach was used as a way to further explore the lived experiences of women diagnosed with stage II or greater gynecological cancer.

Synthesis of Literature

The themes that emerged in the literature were the unique experiences of aloneness felt by gynecological cancer patients, a shift in focus from quantity to quality-of-life, inability to communicate with physicians, treatment effects, long-term survivorship and follow-up care, and the impact of diagnosis as it relates to age. These themes emerged throughout the qualitative and quantitative studies and systematic reviews and were not isolated to individual studies. For example, in an article written by Guenther et al. (2012), the authors acknowledged that women diagnosed with gynecological cancer face uncertainty regarding treatment measures, have a renewed outlook focused on quality-of-life, have concerns related to survivorship and follow-up care, and identify the importance of education regarding the disease.

Each of these themes will now be examined more in depth. A concept that was prevalent throughout the literature was the unique experience of aloneness felt by women with gynecological cancer. This feeling stemmed from a variety of circumstances experienced by the women.

The first was the perceived separation between the woman and her partner. Jefferies and Clifford (2011) and Abbott-Anderson and Kwekkeboom (2011) found women felt distanced from their significant other due to decreased sexual function, physical changes associated with treatment measures, and alterations in body image. Furthermore, in a study conducted by Sprung, Janotha, and Steckel (2011)
with breast cancer patients, the authors concluded that women described feelings of aloneness developed from an inability to express their true feelings and fears related to their diagnosis with their partner and friends. This coincided with the findings of Jefferies and Clifford (2011) in their study of patients diagnosed with vulvar cancer, as well as the study conducted by Howell and her colleagues (2003) in women diagnosed with ovarian cancer. Jefferies and Clifford (2011) also concluded that gynecological cancer patients were embarrassed to speak about their disease due to the disease location. Finally, several studies determined women diagnosed with gynecological cancer were not able to connect with other women facing similar diagnoses due to the rarity of their illness and the decreased survival rate, often less than five years, of other gynecological cancer patients (Beesley et al., 2010; Guenther et al., 2012; Howell et al., 2003; Jefferies & Clifford, 2011).

Building on themes that emerged in the literature, researchers noted a shift in focus from quantity to quality-of-life in patients diagnosed with gynecological cancer. As discussed earlier, a diagnosis of gynecological cancer often coincides with poor prognosis of survival leading to patients reporting a renewed purpose and shift in focus of life priorities (Guenther et al., 2012; Mantegna et al., 2013; Swenson et al., 2003). Another theme identified was the patients’ perceived inability to communicate with their physicians. These feelings stemmed from skepticism related to initial misdiagnosis (Guenther et al., 2012), embarrassment of discussing gynecological symptoms (Jefferies & Clifford, 2011), use of medical terminology (Guenther et al., 2012), and general mistrust of medical professionals (Thygesen, Pederson, Kragstrup, Wagner, & Mogensen, 2012).
Treatment effects, long-term survivorship, follow-up care, and age-related diagnostic implications were the related themes identified in the literature. These themes were prevalent and integrated into several articles. As previously discussed, long-term survivorship in patients diagnosed with gynecological cancer is limited. For those who do survive, lasting treatment effects can lead to premature menopause and the loss of reproductive ability (Barros & Labate, 2008; Howell et al., 2003; Phillips-Salimi & Andrykowski, 2012; Rasmusson & Thomé, 2008). This loss of reproductive ability is most significant for women of childbearing years. The American Society for Reproductive Medicine (2012) identified reproductive capabilities significantly declined after the age of 40 years old with only a 5% chance of conceiving, therefore loss of reproductive capability associated with cancer treatment would typically occur prior to the age of 40 years old.

Furthermore, studies that examined the impact of breast cancer diagnoses in young women determined that younger women experience more psychosocial stressors compared to older women who experience more physical stressors (Climprich, Ronis, & Martinez-Ramos, 2002; Coyne & Borbasi, 2007; Phillips-Salimi & Andrykowski, 2012). Throughout the literature review, similar findings were noted to occur with gynecological cancer patients. Lastly, follow-up care can result in significant stress for survivors (Guenther et al., 2012; Vistad, Moy, Salvesen, & Liavaag, 2011). This stress related to fear of reoccurrence with hypervigilance pertaining to symptom monitoring and testing markers (Guenther et al., 2012).

Another significant stressor associated with the diagnosis of cancer is cancer-related stigma, which can result from personal or societal perceptions and
interpretations of a cancer diagnosis (Cataldo et al., 2011; Howell et al., 2003; Kissane et al., 2013; Shepherd & Gerend, 2014). As defined by the National Comprehensive Cancer Network (NCCN), distress in cancer is the emotional experience that impacts one’s ability to cope with a cancer diagnosis, symptoms, and treatment (Holland, Anderson, et al., 2010). This distress can lead to significant associated symptoms for the patient. These associated symptoms include anxiety, depression, and decreased quality of life (Cataldo et al., 2011; Lebel et al., 2013; Manne et al., 2014). These symptoms can directly impact a patient’s quality of life and can lead to poorer patient outcomes (Cataldo, Jahan, & Pongquan, 2012; Chambers et al., 2012).

Other symptoms closely associated with distress are the concepts of self-blame, guilt, and shame. A belief that an individual had caused his/her cancer was connected to higher levels of guilt and shame (Kissane et al., 2013; LoConte et al., 2008). These feelings of guilt and shame are significant as they may impact an individual's social, marital, and family relationships (Kissane et al., 2013).

Although consistent themes were identified throughout the available literature, further studies are required to expand the body of knowledge as it relates to the lived experiences of women diagnosed with gynecological cancer. Based on the available evidence, gynecological cancer patients encounter unique physical and psychosocial stressors. Further qualitative research is necessary to understand these experiences and their influences on patients’ quality-of-life.

Several gaps in the literature were identified through this literature review. These gaps include, limited qualitative studies that examine women's lived
experiences of being diagnosed with gynecological cancer. Furthermore, the qualitative literature that does exist fails to explore shared experiences across the gynecological cancer spectrum, as it only explores individual gynecological cancer diagnoses like ovarian or vulvar cancer.

Inferences for Current Study

Findings have suggested the current literature focuses on diagnosis-specific experiences with cancer, while no literature has examined if similar experiences occur in all gynecological cancer types. Furthermore, as women ages 18 to 40 years old may have unique psychosocial and physical stressors, it is important to study their diagnoses and lived experience with cancer in comparison to their older counterparts. Finally, it was relevant to explore how patients’ perceptions of quality of life, in addition to that of their family and friends quality of life, change following a diagnosis of gynecological cancer at a young age.

Summary

Review of the literature demonstrates the need to explore women’s lived experiences of being diagnosed with stage II or greater gynecological cancer. This phenomenological research study adds to the body of knowledge of individual and shared experiences of gynecological cancer diagnoses. Furthermore, this study fills an identified gap in looking at women’s collective experiences of gynecological cancer. Finally this study explores how quality of life is impacted, both the patient and family’s, following a diagnosis of gynecological cancer, which has unique and significant physical and psychosocial stressors.
CHAPTER 3

METHODOLOGY

This chapter presents a description of the methodology and research design for the study. An interpretive phenomenological approach, integrated with the conceptual framework informed by Meleis’ transitions theory and Roy’s adaptation model, guided this research process of exploring the lived experiences of women diagnosed with stage II or greater cervical, ovarian, and endometrial (uterine) cancer. This chapter will describe interpretive phenomenology and provide rationale for the utilization of this approach. Moreover, this chapter describes the setting and participants and strategies to protect human subjects within the study. The conclusion of this chapter includes a discussion regarding the gathering of data and data analysis, while exploring the maintenance of trustworthiness and rigor within the study.

Research Design

The aim of this study was to explore women’s lived experiences of being diagnosed with stage II or greater gynecological cancer. The researcher used an interpretive phenomenological approach to guide the study. This method was
chosen because phenomenology aims to “understand the nature or meaning of everyday experiences . . . and to study the essences of experience” (Munhall, 2012, p 129). Benner (1994), Draucker (1999), and Polit & Beck (2012) concur with this definition of phenomenology. The goal of phenomenological nursing research is to identify “how human beings experience phenomena” (Streubert & Carpenter, 2011, p. 88). Likewise, Benner (1994), Draucker (1999), and Polit & Beck (2012) agree with Streubert and Carpenter’s description of the goal of phenomenological nursing research. Phenomenology research centers on the subjective experience of life events and what a particular phenomena means to the individual (Benner, 1994; Cohen, Kahn, & Steeves, 2000; Draucker, 1999; Polit & Beck, 2012; Streubert & Carpenter, 2011). Based on this definition of phenomenology, women are the subjects of this qualitative study, while the phenomenon being studied is the experience of diagnosis of stage II or greater gynecological cancer.

Phenomenology, by definition, is both a philosophy and methodological approach for research (Cohen et al., 2000). Saldaña (2013) proposed that phenomenology allows the researcher to fully comprehend and appreciate the human experience by studying and reflecting on the experiences of the study participants. By understanding specific phenomenon, researchers can understand lived experiences of an individual (Munhall, 2012).

Husserl, a German philosopher (1910/1965), is credited for developing phenomenology as a science and as a research method (Fjelland & Gjengedal, 1994). Husserl emphasized the importance of subjectivity and the humanistic element of experience, and aimed to integrate basic science with psychological experience.
But Husserl maintained phenomenology as a scientific method through the implementation of bracketing, which describes the act of suspending judgment by the researcher, in the research process (Ray, 1994). Furthermore, bracketing prevents the researcher from incorporating his or her personal experiences into the study results (Polit & Beck, 2012; Ray, 1994). By affirming phenomenology as a scientific method, Husserl attempted to validate and authenticate the human experience through description from a first person point of view (Fjelland & Gjengedal, 1994; Husserl, 1910/1965; Munhall, 2012; Rodgers, 2005).

Heidegger (1927/1989), also a German philosopher, expanded on Husserl's works, when he explored the lived experiences of individuals and how they attribute meaning to experiences (Cohen et al., 2000; Streubert & Carpenter, 2011). Heidegger's concept of *dasein* is an essential component of delineating interpretive phenomenological as an approach to understanding the meaning of lived experiences (Dreyfus, 1991). The concept of *dasein*, or one's existence or being-in-the-world, suggests an individual is influenced by past experiences that are essential to help explore and understand human existence (Dreyfus, 1991).

Interpretive phenomenology, based on Heidegger's work (1927/1989), is fundamentally different from the works of Husserl (1910/1965). The goal of interpretive phenomenology, as defined by Heidegger (1927/1989), was to understand the meaning of human experiences and practices (Benner, 1994; Crist & Tanner, 2003; Draucker, 1999; Lopez & Willis, 2004; Munhall, 2012; Streubert & Carpenter, 2011). Furthermore, Heidegger (1927/1989) asserted it was impossible for a researcher to bracket previous experience (Polit & Beck, 2012). Instead, in
interpretive phenomenology the researcher’s previous experience and knowledge can be used as to aid and advance the research process (Polit & Beck, 2012).

Interpretive phenomenological research was developed primarily from the works of Heidegger (1927/1989), who was directly influenced by the earlier philosophical works in phenomenology by Husserl (1910/1965), and later was influenced by the work of Gadamer on hermeneutics (Crist & Tanner, 2003; deWitt & Ploeg, 2006; Draucker, 1999; Gadamer, 2008; Mackey, 2005; Rapport & Wainwright, 2006) and others. Gadamer further developed Heidegger’s work on interpretive phenomenology through the expansion of the hermeneutic circle (Dreyfus, 1991; Rodgers, 2005; Weinsheimer, 1985). Through this process the researcher interprets the lived experiences of individuals by continuously processing the narratives as a whole through the lens of the individual details of the narratives (Dreyfus, 1991; Weinsheimer, 1985). Meaning in the narrative is then found through this continuous process and when it is examined through the context of the individual narrative (Dreyfus, 1991). It is through the “application of hermeneutic interpretive phenomenology, practical acts of living accessed through narratives (interviews and observations) reveal meaning” (Crist & Tanner, 2003, p. 202).

The terms interpretive phenomenology and hermeneutics can be used interchangeably, as both aim to understand the human experience (Polit & Beck, 2012). Plager (1994) delineated the assumptions of interpretive phenomenology as:
(1) Human beings are social, dialogical beings, (2) Understanding is always before us in the shared background practices; it is in the human community of societies and cultures, in the language, in our skills and activities, and in our intersubjective and common meanings, (3) We are always already in a hermeneutic circle of understanding, (4) Interpretation presupposes a shared understanding and therefore has a three-fold forestructure of understanding, [and] (5) Interpretation involves the interpreter and the interpreted in a dialogical relationship. (p. 71)

Through this methodology, the researcher aims to understand the lived experience of the individual being studied.

Van Manen (1990) further advanced the research approach of interpretive phenomenology through the development of thematic analysis. Van Manen (1990) identified six steps in the interpretive phenomenological approach and these steps include: (1) Identification of the phenomenon, (2) investigating the lived experiences of the phenomenon, (3) reflecting on essential themes, (4) describing the phenomenon, (5) maintaining a strong oriented relation to the phenomenon, [and] (6) balancing the research context through the consideration of the parts and the whole. Themes are identified in the data through repeated analysis of the overall narrative (van Manen, 1990). Thematic analysis offered a practical method of hermeneutic interpretation and interpretive phenomenology (van Manen, 1990).

Extending from Heidegger's original works and expanding from Dreyfus' (1991) study on interpretive phenomenology is Patricia Benner's (1994) method for using interpretive phenomenology in nursing research. The goal of interpretive phenomenology is to “uncover commonalities and differences” (Benner, 1994, p. 104). According to Benner (1994) the sources of commonality in phenomenological
research include situation, embodiment, temporality, concerns, and common meanings.

Through interpretive phenomenology significance can be found in the lived experience, including concerns and common meaning (Benner, 1994). Three strategies are used to understand the lived experience of individuals and include paradigm cases, thematic analysis, and exemplars. Interpretation, as defined by Benner (1994), occurs through identifying paradigm cases and exemplars. The paradigm case is when the text is read and analyzed for complete understanding of the phenomenon and a strong instance of concern or commonality is recognized (Benner, 1994). From there, exemplars are utilized to provide and demonstrate themes and patterns within qualitative research (Benner, 1994; Mackey, 2005). Exemplars are key in interpretive phenomenological research, as it "(allow) the researcher to recognize the distinctions the interpretive researcher is making in practice" (Benner, 1994, p. 117).

Qualitative health research, within the context of interpretive phenomenology, allows for scientific understanding of the lived experiences of individuals (Sandelowski, 2004). Likewise, the nursing profession can be further transformed through the understanding of the human perspective and experience (Benner, 1994). This qualitative approach was used in this study as a way to further explore the lived experiences of women diagnosed with stage II or greater gynecological cancer.
Rationale for Research Approach

By utilizing an interpretive framework within this phenomenological approach, significant relationships and meaning can be found within the data (Benner, 1994; Lincoln & Guba, 1985; Munhall, 2012; Streubert & Carpenter, 2011). Interpretive phenomenology, when utilized by nurse researchers, allows the researcher to explore meaning and find understanding in the human experience of health and illness (Plager, 1994; Ray, 1994). For the purpose of this study, the interpretive phenomenological research method, integrated with the conceptual framework informed by Meleis and Roy, was used to explore the meaning, significance, and impact of being diagnosed with stage II or greater gynecological cancer. This research method is best suited to explore and understand which experiences are shared among this population of women. Their adaptation to the environmental stimuli/stressor of cancer (Roy’s Adaptation Model), as well as coping strategies and meaning in the cancer experience through Meleis’ transitions theory.

In phenomenological research, the researcher becomes the “instrument for data collection and must function effectively to facilitate data collection” (Streubert & Carpenter, 2011, p. 89). Drauker (1999) concurred with this stipulation, as outlined by Streubert and Carpenter. The researcher then transforms the information provided by the participants and goes on to identify themes and connections within the data collected (Streubert & Carpenter, 2011; Van der Zalm & Bergum, 2000). Objectivity throughout the interview and analysis process is essential in phenomenological research in order to prevent the occurrence of
inaccuracies in conclusions (Streubert & Carpenter, 2011; Van der Zalm & Bergum, 2000).

Phenomenology allows researchers to understand the human experience, but it is not without limitations. Authenticity in data collection and interpretation is essential. The researcher's awareness and identification of personal assumptions and biases were fundamental to maintaining objectivity and in affirming accuracy and authenticity in findings. Furthermore, because the researcher is the instrument for data collection, the interview guide and conduct of the interview must be clear, focused, and unbiased (Munhall, 2012; Streubert & Carpenter, 2011). Questions were open-ended in order to facilitate communication with study participants because yes or no questions can inhibit communication (Munhall, 2012; Streubert & Carpenter, 2011).

Setting

The setting for this qualitative research study was an outpatient oncology clinic associated with a large regional hospital in the Midwestern United States. Interviews were completed in a private conference room at the outpatient clinic or by phone. The name of the hospital is not specified in this dissertation in order to protect the confidentiality of the participants.

Participants

Purposive sampling was used to generate data in this study. Purposive sampling “selects individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing knowledge” (Streubert & Carpenter, 2011, p. 90). In purposive sampling, data collection continues until the
data repeats, or in the case of phenomenological research, until no new themes or information is generated in the interviews (Streubert & Carpenter, 2011). This concept is known as data saturation (Streubert & Carpenter, 2011). Therefore, the number of participants in the study is dependent on data saturation. It was estimated that 10 to 12 participants would be needed in order to reach data saturation.

Most of the women in this study lived in the regional area serviced by an outpatient hospital clinic. A clinical nurse coordinator in the respective clinic setting identified women eligible to participate in the study and referred them to me (see Appendix B). Once the women self-identified to me, by phone or email, their desire to be included in the study, I then spoke with eligible participants to provide more information about the study and discuss inclusion in the study. Criteria for inclusion in the study were those women diagnosed with gynecological cancer, have a diagnosis of stage II or greater disease state, and were able to read and write in English.

It is important to note, two women who participated in the study were included through snowball sampling. They self-identified for participation in the study through individuals previously associated with the study, but not the clinical nurse coordinator at the hospital clinic. These individuals did not live in the regional area associated with the outpatient clinic and their interviews were completed by phone.
Protocol

After obtaining Institutional Review Board (IRB) approval from Mercer University and the hospital included in the study, I contacted gynecological-oncology patients eligible to participate in the study. Access to the participants was obtained through the clinical nurse coordinator at the hospital, therefore no patient charts had to be accessed during the study. Recruitment for participants began in fall 2017 and interviews followed. The completion date of data collection was August 2018.

Once the clinical nurse coordinator in the respective hospital setting identified women meeting inclusion criteria to participate in the study, I determined eligibility for enrollment in the study based on the pre-determined criteria for inclusion and the information flyer (see Appendix B). I contacted participants by phone to provide more information regarding the study, inclusion criteria, demographic information to be collected, the right to terminate participation at any point, that field notes would be recorded during the interview session, and measures to ensure confidentiality. The date, time, and location for the interview session were then selected.

The anticipated sample size was 10 to 12 participants, although a firm judgment could only be considered as experiences emerged. Recruitment of participants continued until data saturation occurred with available participants. Prior to the collection of data, participants reviewed and signed the informed consent form (see Appendix C). The interview session was scheduled and occurred at a convenient time for the participant. There was an attempt to coordinate the
date and time of the interview with an outpatient clinic appointment to avoid additional travel for the participant. If an on-site interview was not possible with or preferred by the participant, a phone interview was scheduled.

One semi-structured interview of each of the selected participants served as the means of data generation. Interviews were approximately 60 to 90 minutes; longer timeframes may have been difficult for participants with progressive disease states (Streubert & Carpenter, 2011). Informed consent (see Appendix C) and demographic data (see Appendix D), including age, relationship status, lives with, race, work status, occupation, cancer diagnosis, type of cancer, and cancer stage at initial diagnosis, were collected prior to the start of the first interview. The interview was comprised of 13 open-ended questions (see Appendix E). Semi-structured interviews and open-ended questions allowed for participants to share experiences in a flexible manner. Each interview was audio-recorded on two digital devices; transcriptions of the interviews removed all identifying information and included the use of a pseudonym for the participant. I recorded field notes during the interview session and used them to document nonverbal data. I kept a personal journal concerning thoughts and observations about data collection and analysis. Upon completion of the interview, the participant was thanked for her time and insight.

Data Management

Data processing and analysis were completed following the conclusion of all interviews. This is considered an essential step by Streubert & Carpenter (2011). Each demographic data sheet and informed consent were identified by the
participant’s selected pseudonym to maintain confidentiality. I transcribed the recorded interviews into Microsoft Word and backed up the data to an external hard drive weekly. Transcripts were then compared to the digital recording to confirm accuracy. Any identifying information, such as names of the participants and hospital sites were redacted.

To ensure confidentiality of the data, the external hard drive and documents were stored in a locked file cabinet in my home office. My computer utilized in the study was also password protected. The chairperson of my dissertation committee was given weekly updates on data processing, provided access to the digital recordings, and provided transcribed copies of the narratives as needed.

Upon completion of the dissertation process, the digital recordings will be destroyed. In accordance with Mercer University requirements, documents with identifiable information will remain in a locked file cabinet in my home for an extended period of time. These data will be destroyed after the designated timeframe. Interview transcripts will be kept indefinitely, as they do not contain identifiable information and will be used for scholarly papers and presentations. No identifiable participant information will be shared or published.

Data Analysis

The interpretive phenomenological approach was used to analyze the information gathered during the interview process. Multiple reviews of the transcripts at varying timeframes ensured immersion in the data, which is essential to the data analysis process and credibility in qualitative research (Streubert & Carpenter, 2011). Utilizing Benner’s (1994) method of analyzing qualitative data,
the text was read and analyzed for complete understanding of the phenomenon and identification of the paradigm cases (Benner, 1994; Mackey, 2005). A paradigm case is defined as a strong example of significantly meaningful transactions detected through the research and interview process (Benner, 1994; Mackey, 2005). From there, exemplars were identified in the research in order to expand on and substantiate the paradigm cases (Benner, 1994; Mackey, 2005). Finally, themes and patterns within the data collected were outlined through thematic analysis in order to provide evidence of common threads throughout the interviews (Benner, 1994; Mackey, 2005).

Coding

Saldaña (2013) stated that coding of the narratives into short phrases allows for a summative understanding of the lived experience of the individual. Prior to the initiation of coding, each transcript was read in its entirety. Transcripts were then read for a second time with preliminary jottings by the researcher completed in the margins. Saldaña’s (2013) process for first and second cycle coding methods were used to continue analysis of the narratives. First and second cycle coding methods are used to identify patterns in the narratives (Saldaña, 2013). Upon completion of the preliminary jottings, first and second cycle coding were completed manually by the researcher and the dissertation chair independently and compared for agreement.

Methods of in vivo, descriptive, and affective coding were selected and utilized for the first cycle coding (Saldaña, 2013). In vivo coding identifies phrases and words used by the participant (Saldaña, 2013). In vivo coding is useful in “studies
that prioritize and honor the participant’s voice,” in addition to being suitable for beginning qualitative researchers (Saldaña, 2013, p. 91). This coding method also provides an essential step in understanding the meaning and significance to the participant (Saldaña, 2013).

Descriptive and affective coding were also utilized during the first cycle coding. Descriptive coding is also appropriate for beginning qualitative researchers and identifies topics found in the passages of the narrative (Saldaña, 2013). Affective coding is used to explore the emotion and value in the human experience (Saldaña, 2013). Emotion coding “labels the feelings participants may have experienced,” while values coding “assesses a participant’s integrated value, attitude, and belief systems at work” (Saldaña, 2013, p. 105). Both emotion and values coding were identified in the first cycle coding of the narratives.

Values coding is essential in qualitative studies that explore intrapersonal or interpersonal participant experiences and actions (Saldaña, 2013). Values coding can be further distinguished and labeled as value, attitude, and belief. It is important to note that there may be a juxtaposition of what participants state are their values, attitudes, and beliefs, and what is observed in their behavior (Saldaña, 2013). Comparing emotion coding with values coding allowed for the identification of variances in what was the stated value, attitude, and belief verses the emotion experienced by the participant.

Following the completion of first cycle coding, second cycle coding was utilized to further reorganize and summarize the codes generated from the first cycle coding (Saldaña, 2013). *Focused* coding was selected as the second cycle
method and was used to identify themes and subthemes (Saldaña, 2013). Focused coding allows the researcher to compare codes across the narratives to evaluate the transferability of the data (Saldaña, 2013).

**Thematic Analysis**

Thematic analysis is described as the “process of recovering the theme or themes that are embodied and dramatized in the evolving meaning and imagery of the work” (van Manen, 1990, p. 78). Throughout this process, first and second cycle codes are translated into themes and subthemes. From there, final themes and subthemes are identified through reflection and interpretation of the narratives.

Thematic analysis, as outlined by Benner (1994), was used as the primary method to identify meaning within the data. Interviews were analyzed by clustering data coding and themes began to emerge from the shared data (Benner, 1994; Streubert & Carpenter, 2011). Analytic memos were used throughout the coding process, and journal entries assisted with the identification of the codes, themes, and subthemes (Saldaña, 2013). Subthemes were identified within the primary themes of the narratives through reflection of the participants’ experiences of being diagnosed with late stage gynecological cancer.

Interviews were further analyzed by clustering data and themes that emerged from this shared data (Benner, 1994; Mackey, 2005; Streubert & Carpenter, 2011). Based on the aims of the study, transcripts were used to understand the overall impact of the unique physical and psychosocial stressors experienced by women diagnosed with stage II or greater gynecological cancer. Furthermore, this study examined the lived experiences of women with advanced
stage gynecological cancer diagnoses with poorer prognoses, specifically ovarian, uterine cervix (cervical), and uterine corpus (endometrial) cancers. Additionally, interviews were analyzed for concerns related to treatment effects, cancer-related stigma, survivorship, and the impact of reproductive cancer diagnoses in younger women (specifically ages 18-40 years old). Finally, interviews were analyzed for shared experiences consistently appearing across the spectrum of gynecological cancers. Thematic statements were used in the study results to provide examples of the lived experiences of these women.

Trustworthiness/Rigor

Trustworthiness and rigor are essential to the qualitative research process (Saldaña, 2013). I established trustworthiness throughout the research process through a systematic review of the literature, implementation of first and second cycle coding methods, and utilization of Benner’s (1994) method of qualitative data analysis. Lincoln and Guba’s (1985) criteria and techniques guide the establishment of trustworthiness and rigor throughout the qualitative data analysis process.

Lincoln and Guba’s (1985) operational techniques of credibility, dependability, confirmability, and transferability were used to maintain rigor and consistency in this qualitative research study. Lincoln and Guba (1985) maintained that data reliability in qualitative research is contingent upon these four criteria. The outcomes of the study are not predetermined, but take shape throughout the data collection process. The researcher must then interpret and analyze the data through an objective lens, but understand the subjective nature of analysis, as well. These operational techniques allow for an adaptable approach to research,
something that is necessary with qualitative research proposals (Lincoln & Guba, 1985; Streubert & Carpenter, 2011).

Utilizing Lincoln and Guba’s (1985) operational techniques, credibility is maintained through prolonged engagement with the subject matter. Strategies used to establish credibility in this study included reflexivity and the use of field notes and a journal, participant triangulation, researcher expertise as a psychiatric-mental health nurse practitioner, and peer examination of the data with my dissertation chair (Krefting, 1991). My dissertation chair reviewed data processing and analysis to ensure the credibility of the data interpretations. Selection of appropriate quotes to illustrate the themes ensured additional credibility.

Dependability is maintained through the establishment of credibility (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). Dependability was established through a review of the study by my dissertation chair, an additional Mercer University faculty member, and an external committee member. A dense description of the research method was used to ensure dependability (Krefting, 1991). Further techniques of dependability utilized included code-recode procedures and peer examination (Krefting, 1991).

Confirmability is the link between the data collected and the conclusions drawn by the researcher (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). It is theorized the longer the researcher spends with the data the more likely the results can be confirmed (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). Confirmability was determined through accurate and detailed documentation with an audit trail by me throughout the study process. A reflective journal was used to
augment the rich, thick descriptions to further establish confirmability. Peer examination was an additional technique that verified confirmability in this qualitative research process (Krefting, 1991). Finally, assumptions and biases were re-examined to assure findings reflected participants’ experiences rather than the researcher’s presumptions.

Finally, transferability relates to the applicability of the study findings to other study contexts. Ultimately, however, transferability can only be determined by the reader, but depends on the researcher to provide the information to the reader (Lincoln & Guba, 1985; Krefting, 1991; Shenton, 2004; Streubert & Carpenter, 2011). The researcher must, “provide an adequate database to allow transferability judgments to be made by others” (Krefting, 1991, p. 221). Dense descriptions of context, setting, and participants, along with rich data, provide the necessary link between data and other contexts easily identifiable.

Protection of Human Subjects

Steps were taken to protect and maintain the confidentiality of study participants. Prior to the recruitment of participants and data collection, I obtained Mercer University and hospital Institutional Review Board approvals. Written informed consent was obtained for all study participants. Participants were notified of the purpose of the study, given the option to withdraw from the study at any time, and could choose not to answer any question during the interview. Confidentiality was maintained throughout the research process; participants were informed no names or other identifiers would be revealed throughout the study. A coding system was utilized for participant data to maintain confidentiality. Participants
selected a pseudonym for identification purposes in the study. Pseudonyms were identified prior to the interview and were used to identify participants in field notes, audio recordings, transcribed narratives, and all other aspects of the dissertation process. If the participant selected a pseudonym that had already been chosen by another participant, she was asked to select another pseudonym. All study information was secured in a locked data storage device in my home office that is password protected.

Confidentiality

Confidentiality is an essential component of the protection of human subjects. Data generated from the study were reported in such a way that does not identify any individual and cannot be linked to any study participant (Polit & Beck, 2012; Streubert, & Carpenter, 2011). To maintain confidentiality throughout the interview process, all identifying information was removed from the demographic data, audio recordings and transcripts of the interviews, and study reports. Pseudonyms allowed for tracking of the data throughout the study, while maintaining confidentiality.

Interview transcripts generated from the digital recordings were transcribed by me. Any identifying information, such as physician names and hospital setting, was redacted in the final transcript. This information will remain on the secure data storage device for the designated time period mandated by the IRB at Mercer University. All electronic data, including interviews, will be destroyed following the conclusion of this time period. The interview transcripts will be maintained by the researcher, because they do not contain identifying information of the study
participants. Participants were told their narratives will be used for scholarly publication and presentation, but would not contain identifiable information.

Summary

This interpretive phenomenological research study explored the lived experiences of women diagnosed with stage II or greater gynecological cancer. Purposive and snowball sampling was used to select participants primarily from patients receiving treatment at an oncology outpatient clinic at a hospital in the Midwestern United States. Semi-structured individual interviews were used to gather data. Data were analyzed following the completion of the interview to identify themes throughout the data sets. Confidentiality was maintained at all times throughout the study in order to protect all study participants from identification. Finally, Lincoln and Guba’s (1985) operational techniques of credibility, dependability, confirmability, and transferability were used to maintain rigor and consistency throughout the study.
CHAPTER 4
PRESENTATION OF FINDINGS

This chapter provides the results of this interpretive phenomenological study, as well as a summary of data management and analysis procedures utilized in the study. Following data analysis procedures, themes and subthemes were identified from coding of the narratives. Exemplary quotes are provided, capturing the lived experiences of women diagnosed with stage II or greater gynecological cancer. Finally, a discussion of the findings presents a hermeneutic interpretation of participant narratives and the illumination of themes and subthemes.

Data Management

As digitally recorded interviews were completed, each interview was transferred to a digital file on the researcher’s computer. Transcripts were generated verbatim from the digital files by the researcher and checked for accuracy against the recording. Transcribed documents were saved to an external hard drive and printed for the researcher’s use. The committee chair also received a copy of the interview documents by electronic mail.

Participants selected a pseudonym prior to the interview, which was utilized by the researcher in the transcription process to maintain participant
confidentiality. In addition, the researcher coded facilities or individuals identified in the interview sessions in order to further ensure confidentiality. All documents were secured in research files in a locked file cabinet and on the researcher’s password protected computer. Data will be maintained and then destroyed according to Mercer University protocol.

Data Analysis

Data analysis commenced following the completion of the first two interviews and transcriptions of digital recordings. First and second cycle coding methods were discussed and selected with the committee chair prior to the initiation of the analysis procedures. Following the transcription of the data, I manually coded the narratives.

Saldaña (2013) stated that coding of the narrative into short phrases allows for a summative understanding of the lived experience of the individual. First and second cycle coding methods were used to identify patterns in the narratives (Saldaña, 2013). Coding of the transcripts began as soon as each interview session was completed and the digital recording was transcribed. Upon completion of first cycle coding for all ten interviews, second cycle coding was initiated to further compare codes across the narratives to evaluate the transferability of the data.

Analytic memos were used throughout the coding process. Researcher journal entries assisted with the identification of codes and themes (Saldaña, 2013). Field notes and the personal journal, considered sources of data, were used to provide evidence of the data analysis process. Thematic analysis, as outlined by
Benner (1994), was used as the primary method to identify meaning within the data.

The interpretive phenomenological approach was used to analyze the information gathered during the interview process. Multiple reviews of the transcripts at varying time frames ensured immersion in the data, which is essential to the data analysis process in qualitative research (Streubert & Carpenter, 2011). Utilizing Benner’s (1994) method of analyzing qualitative data, the text was read and analyzed for complete understanding of the phenomenon (Benner, 1994; Mackey, 2005). Finally, themes and patterns within the data were outlined through coding and thematic analysis in order to provide evidence of common threads throughout the interviews (Benner, 1994; Mackey, 2005). Once thematic analysis was complete, five primary themes and 12 subthemes were identified for the lived experiences of women diagnosed with stage II or greater gynecological cancer.

By utilizing an interpretive framework within the phenomenological approach, significant relationships and meaning were found within the data (Benner, 1994; Lincoln & Guba, 1985; Munhall, 2012; Streubert & Carpenter, 2011). Interpretive phenomenology, when utilized by nurse researchers, allows the researcher to explore meaning and find understanding in the human experience (Plager, 1994; Ray, 1994). For the purpose of this study, the interpretive phenomenological research method was effective in exploring the meaning, significance, and impact of being diagnosed with stage II or greater gynecological cancer. In addition, this research method allowed for the identification of shared experiences among this population of women across the narratives.
Findings

Participants in this study included 10 women in the Midwest and southeastern United States diagnosed with stage II or greater gynecological cancer. Nine participants identified as Caucasian and one identified as Asian. The average age of the women at the time of diagnosis was 57.2 years old and current age was 59.7 years old. Seven women included in this study were diagnosed with ovarian cancer, two women were diagnosed with endometrial cancer, and one woman was diagnosed with vaginal cancer. Cancer staging at the time of initial diagnosis was one woman with stage II, seven women with stage III, and two with stage IV.

Information in Table 1 gives information regarding the characteristics of the participants, including current age and age at diagnosis, and type and stage of cancer at the time of initial diagnosis. Stage of cancer met the purposive sampling plan, as also identified in Table 1.

Table 1

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>n</th>
<th>Observed Range</th>
<th>Mean</th>
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</thead>
<tbody>
<tr>
<td>Gender: Female</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Current Age</td>
<td></td>
<td>33 to 80 years</td>
<td>59.7 years</td>
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<td>Age at Diagnosis</td>
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<td>25 to 78 years</td>
<td>57.2 years</td>
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<td>Age &lt; 39 years old</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age &gt; 39 years old</td>
<td>8</td>
<td></td>
<td></td>
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<tr>
<td>Type of Cancer</td>
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<td></td>
<td></td>
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<tr>
<td>Ovarian</td>
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<td>Stage of Cancer</td>
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<td>III</td>
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Through the integration of first and second cycle coding, thematic analysis, and researcher reflection of the participants’ narratives, five primary themes were identified. These themes reflect the lived experiences of women diagnosed with stage II or greater gynecological cancer. Identified themes include the existential experience of time, awareness of loss, navigating new waters, sustaining faith, and moving forward. In addition, a total of 12 subthemes were identified in the study.

An outline of the themes and subthemes is provided below in Table 2. Discussion of the five themes follows with exemplars used to illustrate those themes. Verbatim quotes provide evidence and support for the identification of the themes and subthemes.

Table 2

*Themes & Subthemes*

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<th>Theme</th>
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<tr>
<td>The Existential Experience of Time</td>
<td><em>From Then to Now: The Physical &amp; Emotional Experience</em></td>
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<td><em>“The New Normal”</em></td>
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Building on Benner’s (1994) method for using interpretive phenomenology in nursing research, a paradigm case was identified to validate themes and patterns. The participant Lee was distinguishable as the paradigm case among the interviews. Lee’s interview illustrates the five themes identified and 12 of 12 subthemes identified.

Lee eloquently summarized the physical and emotional experience of gynecological cancer, in addition to identifying how these experiences varied in the time leading to her diagnosis in comparison to her survivorship experience. She described how her self-concept shifted as a mother and working professional throughout the cancer process. Throughout these transitional and transformational experiences, Lee identified coping strategies, normalizing and resilient moments, and stigmatization experiences.

Pertaining to the existential experience of time, Lee described how her experience pre-diagnosis was frustrating, going on to explain she knew something was wrong for months before receiving her diagnosis of ovarian cancer. In Lee’s words:

I started noticing I had gained weight in the abdomen, and I noticed I was continuing to have issues with like buttoning my pants. So, so you know I was...was worried. In my gut I knew something was wrong...That period was very very difficult because I just wanted to know...tell me, tell me what’s wrong with me, um, and so you know having to play the wait and see game, we’ll schedule this test, and then, that takes a week. Then it’s another week to see the doctor and then we’ll do another test and it’s another week, um was really really frustrating.

Lee went on to state the relief she felt when she was diagnosed with cancer, as she now had a reason for the symptoms she had been experiencing for months.
Lee described two ways her concept of self shifted during her cancer diagnosis and treatment process, including her identity as a mother and her identity as a working woman. Here she explained the awareness of loss she experienced in her identity as a mother:

“So one of the things that was most stressful to me was I didn’t want my children to see me sick...it was very hard for me to have the tables turned where (my daughter) was becoming the caregiver instead of me being the caregiver.”

Later in the interview, she described the shift in her ability to work full-time, but continued to work part-time during her treatment process, in order to maintain a sense of normalcy, despite the effects of treatment. She stated that without work she “didn’t feel like me, and I needed something to distract me.”

Lee shared there were times when she felt her coworkers treated her differently when she returned to work following her cancer diagnosis. She went on to say that these experiences were not negative, but were a noticeable change from before she was diagnosed with cancer such as bringing her water, checking on her frequently, and helping with chairs.

Lee acknowledged that a great medical team and “lots of prayers and believing in God” helped her survive her ovarian cancer and she described her new outlook on life after completing her treatment for ovarian cancer:

I’ve tried not to work as much. My husband and I decided that if want to travel, we’re going to travel. We laugh and tell the girls we’re spending their inheritance...you know we’re not going wait until I’m 65 or 70 and retired, because quite honestly I don’t know, of course no one knows, but it just brings it home more, I don’t know if I’m going to make it to 65 or 70.
She also described the “new normal” for her daily activities and the long-term effects of her treatment process, including fatigue, memory loss, and peripheral neuropathy.

Lee summarized how the cancer experience has shifted her perspective and given her a new purpose in her life:

So yes even today, so I am 7 months after...after, 8 months after chemo, people still treat me a little bit differently. But, that’s also, I will say, the positive of having cancer and beating cancer has been...I do have a new outlook on life and you know what, work is not who I am, it’s what I do. Yes, I sometimes backslide and I was here until 6:45 last night, but for the most part I’m not going to work 55 (hours)...I’m not coming in every Saturday and work. You know, if something happens to me it’s my family that’s going to miss me. Work’s going to miss me a little bit. They’re going to get over it, and they’re going to hire somebody else that’s going to do my job. Well, my girls aren’t going to get a new momma, and my husband better not get a new wife. And you know my mother’s not going to have a new daughter, so, it kind of gave me a new outlook. (If something happens at work) we’ll fix it. If we can’t fix it, we’ll deal with it. So I’m not going to stress out about it. It’s not life and death. I mean my job’s important, but it’s not life and death. So that...that was a positive that came out of it. The other positive is I try to talk to other women. As my oncologist says, your body whispers to you, you have to listen to it. I had lots of signs. I just didn’t put the signs together.

In addition to Lee’s experiences, each of the women in the study provided rich descriptions of their gynecological cancer experience. The five identified themes reflect the lived experiences of women diagnosed with stage II or greater gynecological cancer. Discussion, exemplars, and verbatim quotes confirm the identification of the themes and subthemes.

Theme One: The Existential Experience of Time

The theme the existential experience of time captures the holistic experience of late stage gynecological cancer. Existentialism is defined as the experience of existence, which includes the meaning of the experience to the individual (Crowell,
Furthermore, Le Poidevin (2015) contended that the perception of time related to a specific event is encompassed more in the sensory perception of the experience than in rigid intervals of time. The theme encapsulated the physical and emotional experiences of cancer, while encompassing the intervals of time in which the women compartmentalized their perception of the experiences. Furthermore, it describes the transitional experience of becoming a well person to an ill person.

Within the theme of the existential experience of time, women discussed their experiences of being diagnosed with and treated for late stage gynecological cancer. Subthemes included from then to now: the physical & emotional experience, health/illness shift, and perception of the future. There were distinguishable differences in the emotional and physical effects of cancer during the diagnosis and treatment process. Participants often differentiated their cancer experience into timeframes of pre-diagnosis, the treatment process, and post-treatment, including their interactions with health care providers. Furthermore, the patient's age at diagnosis often affected the individual's perceptions of time, specifically the future, throughout the treatment process and upon its conclusion.

Subtheme: From then to now: the physical & emotional experience. Prior to diagnosis, participants reported a dichotomy of physical symptoms. Either participants reported no symptoms prior to their cancer diagnosis or they reported seeking treatment for their symptoms multiple times prior to diagnosis, which resulted in a misdiagnosis of their symptoms. Susan, who was stage II at the time of diagnosis, explained she had sought treatment for another gynecological related problem when her doctor discovered the cancer. She stated, “I guess like (in) one
way, if I didn’t have the incident it’s probably, you know, probably bad, because I didn’t know that I even had (a) tumor to start with.”

Although Susan attributed the astuteness of her gynecologist with saving her life, Susan's diagnosis experience was in direct contrast to those experiences of other participants, who were all stage III or IV at the time of diagnosis. These women reported seeking health care on multiple occasions for their symptoms, but were misdiagnosed. These women re-counted timeframes of up to six months from first seeking treatment for symptoms to the time of diagnosis. In Cathleen's words, “I just started out with abdominal pain and it took a while to get that diagnosed. So, the pains kind of started late August of 2015 and, um, I didn’t get diagnosed until January.”

Following the diagnosis of cancer, several women emphasized the shift of physical symptoms they had pre-diagnosis to the physical symptoms they faced during the treatment process. Treatment effects were often identified and reported in relation to surgery, chemotherapy, and radiation. All women in the study underwent surgery to remove their tumors, while nine of ten women received additional chemotherapy and radiation treatments either before and/or after surgery. (It is important to note chemotherapy and/or radiation was recommended for all women included in the study, due to their stage II or greater diagnoses, but one woman chose not to complete chemotherapy treatment.)

Fiona reported the physical effects she experienced due to chemotherapy-related symptoms:
The worst side effects with the standard chemo was what they call extreme fatigue, and that, really, that was probably the hardest part. It would come, maybe, three days after the treatment and that's when it would be the worst. And again (pause), it was just that was really, that was tough. And of course I lost my hair.

Nesman described the symptoms she experienced with radiation:

The radiation to my abdomen pelvic area caused a lot of bleeding, so much so that I just stayed in the hospital, because I was bleeding and it was so painful...beyond painful. And the brain radiation gave me horrific migraines, I was on steroids for a while. I gained 20 pounds.

For some women, the long-term effects of the cancer treatment process were significant. Ivy explained how despite completing treatment, she still experiences physical effects from her cancer. She stated:

Um, there’s still, you know, the fatigue. I still deal with that. So sometimes I don’t have the energy to do what I want to do, but I’m happy with what I’m doing...you do what you want to do, as much as you can, and, you know, yeah there are a few things you can’t do. My arthritis is bothering a little bit more now cause of that hormonal medicine they’ve got me on, but I still go to work, I still, you know, do what I can and keep going.

Susan described the long-term impact her hysterectomy has on her day-to-day function and routine:

If I don’t plan well and if I don’t know what I’m going in, then yes, I do have problems with my bladder or I do have a problem...I do get, um, infections, like yeast infections type thing, very easily, and UTI, and stuff. Those UTI, yeast infections, and bladder issues I get all the time, too. So, I think the physical part too, and like both psychologically and physically I have to plan well enough to do my job in the way I want to. So that’s kind of changed after that.

Similar to the way participants classified their physical experiences in terms of time, emotional experiences were also identified in this manner. The women also identified common emotional experiences throughout their cancer diagnosis and treatment process.
Kada expressed the shame that she felt gaining 70 pounds of abdominal fluid due to her tumor before receiving her diagnosis of ovarian cancer. She described a conversation she had with one of her health care providers following her diagnosis:

I said to, because when I went to go get my paracentesis, I asked the people there I said...I mean I was like 330 pounds and I was huge. My girth was over 80 and it was all in my stomach. Ok, I mean my arms didn’t get big, my legs didn’t get big...I mean, you know how if people are heavy they get, you know, the fat all around them. Well it was all in my middle and, um, so I said to her, I said, “Ok, am I so stupid, am I that ignorant, am I naïve...or what am I...do you get people that come to you that don’t have any idea that this is what this is?” And she said, “yes.” She said, “Ovarian cancer,” she said, “that is the biggest symptom and people don’t know what that is...doctors don’t even realize.” Because my, my primary, had no idea...he just, he told me to get on a weight loss program and to start exercising. He didn’t even think about anything like there could be something wrong.

Kada also reported the embarrassment she felt knowing that her disease had progressed so significantly before she was diagnosed.

In a similar manner, Susan described her experience of being diagnosed with ovarian cancer at a very young age as shameful. That experience has had a lasting impact on her daily life. Susan stated:

I guess in my case I feel...I feel (like) what happened to me, I feel very shameful (about) what happened to me, and like thinking ahead and thinking (in the) future of possibly getting married or, um, you know, having a family...when I think about the future, I often think about having a family, because that’s what I always wanted...but, um, I guess I’m afraid of the reaction that I’ll get...because obviously I would probably have a difficult time having children and stuff. So I think (at) that point I just, I guess, I don’t know if it’s lost interest or maybe, um, I’m making (an) assumption that, you know, who wants to get married to (someone) who cannot give them children? Because, you know, like I’m still the childbearing age and most likely (giggle) someone I would date or someone I would marry would probably be in the same age area. So I think that kind of relationships wise, um, I...I did, you know, lose interest, even personally trying to date someone or something like that.
Nesman, who was also diagnosed with late stage vaginal cancer at a young age, reported her fear of the unknown:

I mean my biggest concern is for my daughter. I want her to, you know...I want to be there for all of her big things that come up in life and I’m hopeful to just stay cancer free. And my husband, needs uh (long pause)...I don’t know...uh, he’s not going to really change, definitely not devastating changes. So I, I don’t know, I just hope that I get to be here for the rest of that and if I’m not then I worry about the two of them and how it will affect their personalities and their futures. Yeah.

Subtheme: Health/illness shift. Health/illness shift as a subtheme describes the spectrum of the women’s experiences of being diagnosed with and treated for late stage gynecological cancer. It also encompasses the shift in the perspective of being a well person to a person with a life-threatening disease. These experiences created a shift in the physical health and emotional well-being of the individual, while also creating a value shift in what is important to the individual.

Through the application of Meleis’ transitions theory, an appreciation of the health-illness transition of women diagnosed with stage II or greater gynecological cancer occurred. The health-illness transition in this instance pertains to the individual’s perspective of the transition from a well person to a person diagnosed with cancer (Meleis, 2010; Schumacher & Meleis, 1994). Several women in this study underwent this health-illness transition at multiple points throughout their cancer experience, when a relapse of disease occurred. Understanding the health-illness transition process for women diagnosed with gynecological cancer was inherent to the purpose of the study.

For some women in the study, the shift from health to illness was a gradual shift. But for Cindy Lou the transition became apparent immediately, due to
modifications she had to make in her home environment. She shared how she had 24 hours to place her ailing mother in a new home and prepare for surgery following her diagnosis:

I was the strong one and I didn't shed any tears at that point (nervous giggling). I did after. Um, I called my siblings, I emailed them and said I need help with mom. I had to get her placed, because if I have to go through chemo and radiation, which is probably the minimum after surgery. So my twin brother called right away and said, “I'll take her.” So we got her moved there that following Sunday and then Dr. UXU called and said, “somebody cancelled, I'm going to do you on Tuesday”.... it got moved up quite quickly. We had 24 hours to get ready. Get my bedroom from upstairs moved downstairs, because my mom was in the downstairs bedroom. So, everything really, really happened fast once I actually got somebody to act for me.

Susan also explained how her cancer diagnosis was an unexpected and stressful experience. Following the surgery to remove the tumor, she described the moment she understood the impact of the diagnosis and illness:

I guess I would say that, um, I remember I didn't feel anything. It was almost like (a) numb feeling. And I guess I understand the medical terminology well enough...but I think my coping mechanism was completely destroyed at the time. I didn't have good judgment. But I think the most stressful was that I knew, um, I didn't have insurance and I knew I (would) have to pay this one way or another way.

For other women, the health-illness transition was apparent even leading up to the diagnosis, due to the physical symptoms they were experiencing. Nesman stated how she felt the shift prior to the confirmation of cancer and how that shift continues to present day:

When I started to not feel right, I was just super-duper tired and then right after I was diagnosed I was going through treatment I was super tired and ill. And (long pause) now, my life’s a lot like what it was before I was diagnosed with cancer. Stay at home mom, I coach cheerleading; and I don't have as much energy as I used to, but... (trailing off). Yeah, a little bit. I think I’m more apathetic than I was before.
In addition to the physical stressors associated with the gynecological cancer experience, women who participated in the study reported the psychosocial strain they faced. Ivy described how the perception of now being ill affected her daily thoughts and emotions:

I mean, don’t get me wrong, there were days when, you know, I would feel a little low. I’m human, I’m going to do that, you know, and wonder am I going to beat this. And I’d just look at myself, think to myself, “yes I am, I’m going to beat this.” I’ve got too much to live for. I’ve got five grandchildren.

Cathleen was among participants who were diagnosed with late stage gynecological cancer more than once. She illustrated the difficulty of facing the health-illness transition multiple times and the emotional toll these multiple transitions had on her:

I was calling everybody...giving all my good news and I thought, “ok, you know, I’ve whipped this.” (Tearing up). Well, that was a little naïve. (Crying). I cry about that because (strained voice)...you think you’ve done everything and the result is good. And you think you’re all clear and home free and you’ve made it through. And so I felt wonderful for a few months, even though I was still having some after effects of the chemo and all of that. And then the following winter my pain came back, so six months, and (long pause)...that was so devastating (crying), because I wasn’t prepared for that. I don’t know whether I didn’t listen or I fooled myself or what, but I did think that I had, I had beaten it and then when you realize you haven’t (strained)...that was so hard, so hard. But, I picked myself up again, and “ok, what do we do now.”

*Subtheme: Perception of the future.* As the women reflected on their experiences of being diagnosed with and treated for cancer, many of the participants described how their perception of the future shifted. This perception typically coincided with the awareness of increased mortality and a reduced life expectancy following a late stage gynecological cancer diagnosis. Some women
described how their personal perception of the future changed, while others explored how their perception for their family’s future was impacted.

Lisa illustrated how her perception of the future shifted immediately following her diagnosis and continues to impact her:

You could say it’s negative or you could say it’s sobering too...I didn’t dwell too much on this, but of course before I started chemo, so that would have been in December of 2016...you ask yourself things like is this going to be my last Thanksgiving? Is this going to be my last Christmas? You know that kind of thing. And even now I go, well...am I going to be around here next year to do this? I don’t dwell on it, but those questions, you know, once in a while when there’s an event crossing my mind.

Cathleen eloquently summarized how her perception of the future changed for her personally following her initial ovarian cancer diagnosis and how that perception changed further following a relapse diagnosis:

The most dominant thing is not knowing what my future holds and I know we never know...totally know our future, but we have some pretty good ideas. I always said I was going to live to be a hundred. Half joking, but serious about it, too...and now I know that’s probably not going to happen, so ok, I just have to deal with that. And I hope things go really well for me, but if not I’ll have to prepare myself in the best way that I can (choking up). And I don’t (know) what that’s going to be. I live with that knowledge that there will probably be a next time when I am no longer in remission and then I’m going to have to go through steps again. And so, I wonder, how many times? What’s in store for me? How many times will I be going through this process before I either die or am cured? That’s what I think about most, how many more times? And (choking up) will my strength be there? I mean going...losing my remission the first time was horrible for me. I was devastated. If it happens again, I don’t think I’ll be as devastated. It’ll be hard, but I won’t be as devastated, cause I’m more aware now of what my life can bring me dealing with this disease. (Long pause). And that’s a good thing. That’s a good thing, too. You can’t get hit in the head over everything, you know, you just...sometimes it has to just be a slap up against the head and move on. Because I can’t take...I just felt like I couldn’t take any more super whammies. That was hard...that was hard. But I feel like I’m more prepared now.
The theme *the existential experience of time* was used to capture the holistic experience and identified common timeframes experienced by participants with late stage gynecological cancer. Meaningful timeframes in the cancer experience were not predetermined by the researcher, but were prevalent in the way each of the women outlined and described their experiences both physically and emotionally. It was evident that the women intertwined their physical health with psychosocial well-being and that they encountered shared experiences across the health/illness continuum, as they experienced the shift from seeing themselves as healthy to seeing themselves as ill. For these participants being ill was a relative term, as some experienced the shift multiple times because of recurrence and retreatment of disease. Future time was assigned a greater value following the cancer experience, as health and wellness became more meaningful to the women when comparing it to illness. In addition, the women’s perception of quality of life, both during and after the cancer experience, was largely attributed to the their emotional and physical health.

Theme Two: Awareness of Loss

The theme *awareness of loss* captured the observed experience of loss each woman noted during the cancer diagnosis and treatment process. During this process, women acknowledged major changes in *the concept of self* and a reduction in *moments with family and friends*. An individual’s perception and awareness of how they are viewed by others, extends from both societal and cultural values (Gallagher & Zahavi, 2015). Husserl maintained self-consciousness and self-concept are connected to the individual’s social interactions (Gallagher & Zahavi, 2015).
Subtheme: The concept of self. For the women in this study, their concept of self often shifted or changed during the treatment process for cancer. The concept of self, for the purpose of this study, relates to the individual’s perception of their role personally and societally. Roy’s adaptation model (2009) contributes to the understanding of how the societal role identity of women diagnosed with gynecological cancer can shift, as perceived value to society may decrease due to illness. Furthermore, through the application of Roy’s adaptation theory (2009), an appreciation of how gynecological cancer may affect personal identity, family, and society due to the perceived decrease in value by the individual and society.

Lee described two ways her concept of self shifted during her cancer diagnosis and treatment process, including going from being a caretaker to being cared for, as she explained:

So one of the things that was most stressful to me was I didn’t want my children to see me sick. Um, one of my children is, is a nurse, so she understood a lot more of what was going on than the younger child. And it was, it was very hard for me to have the tables turned where she was becoming the caregiver, um, instead of me being the caregiver. Either she or my husband went with me every single day to chemo, and sat with me and we were there on what I called my long weeks, week one, we were there 8-9 hours each day. Um, so that was the biggest thing was I didn’t want anybody to see me as sick. I refused to let anybody refer to me as being sick.

Later in the interview she described the struggle in thinking of herself as a working woman as she attempted to continue in her previous work role, in order to maintain a sense of normalcy:

I wanted to work. Human resource policy is if you’re out on leave, you’re not supposed to have access to email or you know the work network and that sort of thing. I was able to convince them that I had to. That without that I didn’t feel like me. So I was able to, um, convince them. It made me feel good. I’ll be honest, I didn’t do a lot, but knowing that I had that access and I could
check an email here or there. I had this bright idea that I was going to work through chemo. Um, obviously week one of every cycle I knew I couldn’t work because it was all day, every day, for the entire week. But, I thought I was going to work Tuesday through Friday on weeks two and three. It didn’t work out that way (laughter). Yeah, I might have worked a couple days. Or I might work two or three hours at the house on a laptop, but um, not being able to work made me feel like less of myself.

Susan, who was single at the time of diagnosis and had no children, continues to not actively explore relationships due to loss of reproductive ability. For Susan, her concept of self and value to a potential partner was innately tied to her ability to bear children, which she lost when diagnosed and treated for cancer at the age of 25. She described an interaction with a counselor relating to her inability to bear children:

I think I do need to have better coping. See, because even my counselor told me once, um, you might be making assumptions that no one wants to get married because I cannot have a kid or because I may have cancer later. I’m kind of making all these judgments, so that’s probably not a healthy way to think...I guess I’m afraid that it’s been...it has been a very, very hard process for me and I’m afraid if someone were to come in my life, then that person is going to have to share what I’ve went [sic] through. So that’s the part that I don’t want, (I don’t want) anyone to take my burden. So, I think that’s one way I’m thinking, you know, I don’t want to put this on anyone.

Subtheme: Moments with family and friends. The subtheme of moments with family and friends captured the decreased socialization during the cancer treatment process and perceived loss of time due to mortality concerns. The perception of loss of time and moments with family and friends occurred concurrently throughout the gynecological cancer treatment process and following completion of treatment. The women often described how the significant treatment effects impacted their daily activities and relationships, due to reduced social interactions. Kada explained:
Yeah, yeah at that time and now, no we don’t really travel much, like I said, I’m very fortunate we have five children and they all live, you know like, miles within each other and of us, too. They would be the ones that we would see more, but um and we got some friends that live out in ZXC and we haven’t seen them because of just the travel, and you know things like that...

Cindy Lou also identified how the treatment for her endometrial cancer impacted her relationships stating, “Well, I’ve had to stop going to church when my counts were low. That was hard, but people would call me.” She went on to detail how fortunate she felt that her social activities were returning to normal now that she had completed treatment:

But I’ve got pretty much everything that I had been doing before my diagnosis, I was a funeral lunch coordinator at church, so I’m back to doing that. Going to the committee meetings that I was skipping during my diagnosis and treatment. I think I’ve gotten pretty much back into the swing of things.

Cathleen described how her perception of future time with her family shifted following her diagnosis:

You know, and this is going to sound very self-centered, but the prime thing I think about is how much I’m going to miss them. (Choking up). And miss being in their lives. (Crying). So, I know they’ll miss me and they love me, but it’s just that I want to be there for their lives. To watch their lives proceed and my grandkids...my grandson just graduated from VBC High and he’s off to college and honors program. I want to see where his life goes. (Choking up).

She later went on to explain in the interview the future loss that she feels so prevalently following her cancer diagnosis is time with her husband, children, and grandchildren due to facing her own mortality. She stated:

I know that when I’m gone, they’ll be ok, cause they have good foundations and my son and daughter-in-law are wonderful parents for the grandkids. And I know my husband will have a terrible time, but um, they’ll be fine...they’ll all be fine, because we have good family support, but I just...I just don’t want to have to miss them. I just don’t want to have to miss their
lives...you know, they tell me that I’ve got a couple of years, now that’s an average...some don’t make it that far, some make it further, but it really hit home with me that I really had received a death sentence. And you go through your life not knowing when you’re going to die (strained) and that kind of makes things easy. And we all know deep down that we can die any time, but when you know that “ok, I’ve got...I don’t have time into the future...like unendless.” It’s kind of right there. It’s my near future probably, maybe not, but probably...and so that’s really, really difficult to deal with, because on the one hand I’m a very optimistic person, so I feel optimistic...but I’m also a realist, so those two things fight in me all of the time. (Crying). And you don’t want other people to know that.

The theme awareness of loss extended from the associated value and significance each of these women placed on their concept of self and time with family and friends. While each of the women could assign meaning to any experience encountered during the gynecological cancer diagnosis and treatment process, the women in this study identified shared experiences and anticipatory losses in their perception of social and personal roles with respect to their relationships and others. These experiences were also shared across participants regardless of gynecological cancer type, stage at diagnosis, and age at diagnosis.

Theme Three: Navigating New Waters

Navigating new waters, consisted of three subthemes: feelings of relief, the stigma of cancer, and maintaining the status quo. Navigating new waters encompassed the unique and paradoxical emotional experiences the women encountered during their diagnosis with and treatment for cancer. These experiences resulted in the women facing newfound and uncommon feelings of relief with diagnosis, the personal perception and associated significance of stigmatization, and defying personal and societal identification of the sick role.
Subtheme: Feelings of relief. Feelings of relief with cancer diagnosis was noted by several participants. Diagnostic delay was common among the participants in this study and was frequently associated with the primary care provider's lack of knowledge or dismissal of gynecological cancer symptoms. Once the diagnosis of gynecological cancer was identified, participants reported a sense of relief with diagnosis and an increased determination to tackle the obstacle head on. This finding was unique to this study, as relief is an uncommon emotional experience when diagnosed with cancer and was not previously identified in the review of the literature.

Kada and Cindy Lou both experienced significant timeframes of diagnostic delay of their gynecological cancer. Kada reported a six-month period of weight gain related to the collection of 70 pounds of abdominal fluid before diagnosis. During this time, she had sought treatment from her primary care doctor on multiple occasions and her concerns were ignored. When the diagnosis of cancer came, Kada stated it was a relief:

So when I found out I had cancer, my reaction is probably totally different than anybody else's...I was relieved. So, that it wasn’t me getting fat, but it was cancer, and it’s like ok now what do I do?

Cindy Lou described a similar feeling of relief and sense of resolve when the source of her symptoms was identified as cancer. She stated:

Yeah, being frustrated, knowing something was wrong and not being able to get diagnosed. It was kind of almost a relief, as crazy as that sounds...just to get diagnosed and to get going on treatments.
Nesman also shared that while she did not want to have cancer, she was comforted when they found the source of her symptoms. She said, “I knew there was something wrong. I had no idea what it was. I was happy that they identified it.”

Similarly, Lee explained the relief she felt when she received her diagnosis and began her journey with a gynecological oncologist:

So the night that I was diagnosed that I have this tumor, the gynecologist told me she was going to try to get me in with a specialist. She called me the next morning...she said, “I’ve talked to him, um he’s the only gynecological oncologist in XYZ and he’s going to get you in today.” I immediately felt a sense of relief.

*Subtheme: The stigma of cancer.* Personal or societal perceptions and interpretations of a cancer diagnosis may result in health-related stigma (Cataldo et al., 2011; Kissane et al, 2013; Shepherd & Gerend, 2014). Health-related stigmas may be perceived by the individual based on his/her internalized feelings of shame associated with a medical diagnosis, or may be enacted by members of society when actual discrimination occurs (Lebel et al., 2013; Shepherd & Gerend, 2014). Internal (or personally driven feelings) and external (societal or culturally driven feelings) stigmas of cancer were described by several of the women in the study. The women also described the personal impact each of these stigmatizing episodes had on them when these episodes occurred.

Nesman detailed the first time she was seen in public when chemotherapy had resulted in her losing all of her hair. She described the anxiety she felt when recounting this event:

I just didn’t like being bald. I went to...my MRI...and I had on this cancer hat. It was nothing, just cotton fabric sewn together like you see people wear, and they loaded me up with the IV and I drank the stuff and I was just sitting in
the back. I had like wispy, nasty head of hair, like spots and everything. I had my cap on, and I asked the lady if I could leave the hat on for the test and she was like “no, you're going to have to take it off, we've had issues with that.” And so I was upset because I had never shown anyone my bald head. And then they left me back there for over an hour because there were like emergency patients, I guess, that came in and needed to get their scans, and I just worked myself right up. Until I walked out into the hallway and shouted at this lady to rip this thing out of my arm or I was going to. She came in, took it out, and I left. (Laughing). Yeah, that part was...I just had a hard time with the whole “I'm bald.”

When asked about her experience of losing her hair, Cathleen shared this feeling of exposure she associated with being bald:

> It's just so foreign to the way you've been living your life and all of a sudden you're very vulnerable. And even a bald head makes you vulnerable (tearing up). You know, so you're wearing goofy hats and everybody that sees you wearing those scarves or hats, they know.

When Susan shared her experience of being diagnosed with cancer, she described the shame and fear she felt prior to disclosing her diagnosis with her family due to the cultural expectations of perfectionism in the environment of her childhood. It was this cultural concept of perfectionism that kept her from sharing her diagnosis with her family until absolutely necessary, when she knew they were going to learn of her diagnosis through another means. She explained:

> Umm, because I think I grew up in a culture that, you know, you try hard, everyone has to try (to do) their best and we have to make it perfect. Even if we try that and we don't get it, (then) still it’s our fault that, you know, we didn’t try hard enough...I think... I think I told them (about my diagnosis) within like three months. . . . I had to tell my family members that I'm processing this and this is what happened. I would say it was like probably 3-4 months later.

At the time, she recalled it was easier to go through the experience of cancer alone than to face the potential shame she could bring to her family with her diagnosis and perceived failure.
Subtheme: Maintaining the status quo. Several women recognized the importance of maintaining the status quo following their diagnosis. While cancer became a large part of their life, they did not want it to characterize them as a person or influence their actions. Maintaining the status quo became an integral component of their survivorship. While change was acknowledged, it did not define them as individuals, and these women hoped to avoid being characterized as a cancer patient.

Multiple times during her interview, Ivy reiterated the power of positive thinking and the importance of maintaining life as normal as possible for her and her family. She said:

We tried to keep as normal as possible, because if you don’t, you’re gonna get depressed and that’s not going to help you. I mean it’s not going to help you to be depressed all the time and think the worst all the time. You know, you’re going to have moments of thoughts [that are] not good, but...being positive is extremely important to me.

Lee noted that the did not want her family to see her as sick and how it impacted her internally when she was struggling to prepare for the holidays and had to ask for help. She stated:

I actually started chemo the week after Thanksgiving and even my extended family, I’m the oldest child, so I’m used to planning the family get togethers. Psychologically it was very frustrating and it was a downer that I couldn’t do it. Yes, we still had a...a family get together and, um, it was great, but I hated that my daughter had to pick up my, what, what I considered my slack.

She went on to say how she tried to reduce the impact of her cancer on her family and work by trying to limit how they viewed her when sick. Ultimately, she tried to reduce the impact and associated stigma of her disease. She recalled:
I would not let my mother come to a single treatment...[she] lives 20 minutes away, I didn’t see her very many times during my treatment because I didn’t want her to see me sick. Yeah, I didn’t want anybody to worry about me. I wanted to work.

The theme of navigating new waters encompassed the incongruous emotions the women confronted during the experience of cancer. This theme incorporated the paradoxical emotions of the women in this study and how they handled this newfound phenomenon. In addition, it captured moments where the women were characterized as a cancer patient, a stigma they fought desperately to avoid. These experiences led to a shift in the attitude and beliefs of the women, which ultimately resulted in the acceptance and understanding of how their lives had changed since their late stage gynecological cancer diagnosis.

Theme Four: Sustaining Faith

Sustaining faith was a predominant theme identified in a majority of the interviews. The women in the study described ways in which their faith sustained them, even during the difficult periods, during the cancer diagnosis and treatment process. Many of the women attributed their ability to survive this arduous time directly to their faith. Subthemes of belief in a higher power and purpose in the experience developed from the theme of sustaining faith. While not a prevalent topic in the literature review, faith and spirituality became a noteworthy theme in the experiences of late stage gynecological cancer described by the women in this study. In eight of the ten interviews, the women reported the significant role their beliefs had on their experience with advanced stage gynecological cancer.
Subtheme: Belief in a higher power. The subtheme of belief in a higher power encompassed the traditional Christian beliefs the women had in God as the creator of the universe. Furthermore, it identified the significance each of the women placed on their relationship with God and how that relationship sustained her throughout the cancer experience. Kada described her belief in God and the feeling that it was going to be ok:

I mean I am very religious and I believe God does miracles, and when I was first diagnosed with it, um, I just knew I was going to be ok. I just knew God was...this was going on for a particular reason, um, I am going to be used as his disciple. And, and I knew right from the very start that it was going to be good and it was. It was...it was a miracle and yet it was...so, I wasn’t nervous, I wasn’t scared. I knew that.

Ivy consistently attributed her strength during the cancer diagnosis and treatment process to her belief in God. She said, “God was my co-pilot and I truly believe that positive thinking and believing in God will get you through anything.” Kada shared a similar philosophy when stating, “God’s got a plan for me...God will listen to you and...if it’s in his will, you’re going to be...you’re going to be good.” Julie also shared that her Catholicism and “true belief in the Lord” brought her comfort during these difficult times and she attributed part of her cancer survivorship to a healing mass she attended.

Subtheme: Purpose in the experience. For many of the participants in the study, finding meaning in their gynecological cancer diagnosis brought them a sense of purpose. Ivy described this purpose in her experience:

I did feel kind of like I had a big weight put on me when they diagnosed me, but I knew I was strong enough. In fact my oldest son he says, “mom, why did God let you get cancer?” I says, “honey, cause maybe he believes that I’m strong enough to make it through here, this road trip, and I can help other
people navigate this road trip when they’re diagnosed.” And that’s been my mission ever since.

Kada also reflected on a time her daughter wrote messages of hope on her van and it became a way to share her faith and experiences with cancer.

Yeah. Yes. I think they were just, um, more...just more happy, more amazed and thankful and prayerful that, you know...they saw how there was hope. What we did was is once I, once I was done with cancer, uh, we wrote...my daughter got out and surprised me and she took the window chalk and she wrote on my back windows all, we have a van, and she wrote all around the van, except for the windshield, um, cancer free and she wrote it all on there. And God heals and all that and, um, we left it on there forever...so many people would either beep the horn or they would come to us and they’d say, “thank you, I needed to read that” and you know, I would say, “there’s hope, just keep on hoping, and...keep praying.” And so...if anything I think they got more of a, um, a hope for themselves. You know, I mean, they got...they got more positive.

Even after her cancer returned, Cindy Lou maintained there was a reason for the relapse and higher purpose in her experience:

Oh, absolutely, because I know God has a reason for it and I just have to find out what it is and go with it. (Long pause). And even if it does come back, I’m sure he has a reason for that too. That it’s going to reach somebody, somehow. (Long pause). Time will tell.

The theme sustaining faith emerged as women sought to find meaning in their experience with cancer. Throughout the cancer diagnosis, treatment, and healing process, the women’s relationship with God provided them a reason to persist when facing almost insurmountable odds. For a majority of the women in the study, faith and purpose in the experience became major coping strategies for them as a cancer patient and later as a survivor. In addition, the women were able to find meaning and purpose in their cancer diagnosis and treatment process, through the strengthening of their convictions and sharing their story.
Theme Five: Moving Forward

The final theme, moving forward, captured the strategy for coping following the diagnosis with and treatment for gynecological cancer. Meleis’ transitions theory and Roy’s adaptation model provided the conceptual framework for this study. It is in the theme of moving forward where a comprehensive picture of women’s experiences of being diagnosed with stage II or greater cancer was revealed. Furthermore, in this theme the long-term coping strategy of the women was revealed. Meleis’ transitions theory, as a part of the conceptual framework, provided further understanding of the women’s experience of being diagnosed with stage II or greater gynecological cancer. The subthemes of resiliency and “the new normal” emerged within the theme of moving forward.

Subtheme: Resiliency. Resiliency was a prominent subtheme identified within the theme of moving forward. Participants described their perceptions of what being diagnosed with cancer meant to them and most participants alluded to the notion of adaptation and surviving at all cost. Roy’s adaptation model was utilized to enhance understanding of the shift that can occur following a cancer diagnosis and the health-illness transition. Roy proposed that a person is a biological, psychological, and sociological individual who is consistently interacting with his/her environment and changes in the environment that will subsequently influence the behavior of the individual (Roy, 2009).

Understanding women’s perceptions of the stressors within their environment associated with a diagnosis of gynecological cancer was a major focus of this study. In addition, the study explored the associated meaning and value of
the stressors identified by individuals participating in the study, while exploring the individual’s response to the stressor of gynecological cancer. The subtheme of resiliency developed from an understanding of the individual’s response to that stressor. Nesman discussed the importance of appreciating each moment:

I mean, I still think I’m going to live ‘til we’re old and grey and sitting on the porch together. And, I just...I do now, um, value each day more and I’m happy for the next day. But as far as the future, we’re just sticking to the same old plans we’ve always had.

Cathleen and Ivy shared similar views of adaptation and resiliency. They each described the need to face the health/illness transition head on and the reasoning behind their strength. Ivy stated:

I mean, I’ve got three older grandchildren... I’ve got a lot to live for and I wasn’t just going to sit down and accept the diagnosis. I’ve always been a fighter and I always will be...I tell everybody, it’s very important to keep a very positive attitude. Yes, you’re going to have days. I cried; I wouldn’t be human if I didn’t, but you got to keep a positive attitude and believe that you’re going to do this. That you will get over that hump in the road.

Cathleen articulated her rationale for being persistent in spite of her cancer reoccurrence:

This was all new to me and I just told myself, “you’re going to do whatever you’re told is the best course for you.” And I know there are some people who choose not to do certain things, and I’ve thought about that and I wonder how...why do people decide to forgo some things. I don’t understand that, because I want to live...I want to do whatever is necessary to prolong my life as long as I can. Yeah. And if it hurts (crying), ok, I can deal with that. If it’s not fun, I can deal with that, and I’m going to throw up, I can deal with that...I’ve been very fortunate in dealing with the chemotherapy, um, and with the olaparib, the Lynparza that I’ve been on. My side effects with that are so minimal, that I know that I’m one of the fortunate ones, because I have fatigue and I have occasional heartburn, but that’s it. And I know there are women who go through dealing with awful side effects, so I consider myself very lucky.
Just as Cathleen has had experience being diagnosed with cancer more than once, Julie has experienced a reoccurrence of her late stage gynecological cancer twice. She explained her reasoning for continued resiliency:

I have been very fortunate and very blessed, that's all I can say. You know, cause when I first heard that “you have stage IIIC,” I think like “you know that’s a death sentence, I’m right next to stage IV.” You know, and you always think people that are in stage IV don’t ever make it and I really, after that first one, I didn’t think I was going to make it. You know you go through the treatments and they’re horrible...or at least my first round of it was horrible...I sat home a lot and didn’t really want to go any place because I didn’t want to pick up any germs from anybody else...it’s kind of a tough road...I guess you just can’t stop fighting. You know, like I said...I kept wanting to not do it ever again, but here I’ve done it three times and I’ve still made it and I would do it again. Even though I don’t really want to, but I will if I have to.

Subtheme: “The new normal.” The subtheme of the “the new normal” was used to identify the adaptation to cancer and the transition point to survivorship. A description of adaptation and stressor from Roy’s (2009) adaptation model is that a change in the environment of the individual will cause stress and this environmental change will subsequently influence the behavior of the individual and cause the individual to adapt to their new environment. The adaptation to the stressor cancer in this case produced the classification of the subtheme “the new normal.”

As Nesman previously described, Fiona also noted a shift in her physical well-being following the completion of treatment. Fiona discussed how this change has adjusted her activity levels:

Other than the extreme fatigue...I feel like I came through it pretty well. I was pretty healthy going into it...I just can’t walk as far as I used to, can’t travel as much as we used to, that kind of thing, but that could have come with age too and cancer might not have anything to do with it.
In addition to a new normal as it relates to physical function, several of the women noted an adjustment in their approach to stress and respective emotional states. Cathleen noted at times she continues to feel overwhelmed by her cancer experience:

The emotional stress can come out of the blue. I’m, you know, I will think that I’m dealing good and happy and going along and in my day-to-day life, and then all of a sudden it will just...poof...wash over me. And, it might take me a day or two to get through it, but it really colors my world hugely when it’s happening. And, so I just...you know, I’ve just learned to deal with that. But by and large, I...I feel like I’m handling it really well in that I have minimal stressors. I really...I really believe that and sometimes when I do, I’ll just cry or, you know, I’ll pick on my husband. That relieves it, too! Bless his heart, he puts up with it. But, yeah...when I’m going through those periods I really feel it. I really feel it and then it almost seems to go away from the place it came from. In the same way, just seems to flood over you and then flood away, you know, for a while. That’s the only way I know how to explain it. It’s not constant.

In contrast to Cathleen’s experience, Julie shared she is now more carefree because of her gynecological cancer diagnosis and treatment:

Nothing stresses me anymore. And you know, that’s how I look at it, I think, you know, I’ve got to take each day and enjoy every day. I used to be the type of person I cleaned my house every Saturday. You know everything...was organized, and I don’t do that anymore. If somebody calls me, it’s like, ok, I’m ready to go. Where before I’d say, “well, you know I got to get this done, maybe I’ll talk to you later” or...I try now to make the time for anybody that wants to do something, so....

Susan explained how she changed in a positive way during her cancer diagnosis and treatment process. She noted how her previous perfectionism shifted to a more relaxed approach to life:

Like before I thought if I try hard enough, I can get it, you know what I mean (laughter). I always tried hard, pursued something, and I’ll get (it) in return (for my) hard work...after the diagnosis I started feeling, um, there is always a limit (to what) I can...what I can do. And I still try my hardest to try hard, you know, the hardest that I can try, but um, somehow I’m more relaxed. I
guess I’m more relaxed to think, uh if...if I don't achieve some goal, it’s ok. It’s not a big deal because I did my best. But before, um, I have to, you know, accomplish the goal, otherwise I would feel very guilty...or I would feel very bad. I think the incident really told me that there is something that I cannot accomplish no matter how I try. That one thing that is kind of interesting to see (is), um, more of the thinking part of my life has changed before and after.

The final theme, moving forward, provided the most comprehensive depiction of the transition experience of the gynecological cancer process. The women recognized the strength they showed throughout the cancer experience and their ability to cope throughout this time. In addition, the women acknowledged they were no longer the same person they were when they started the cancer journey, both physically and emotionally. Their quality of life shifted, both positively and negatively, throughout their cancer experience. The conceptual framework was most clearly illustrated as a whole in this theme. This theme distinguished the ability of the individual to adapt to stress of cancer, while acknowledging what transpires after the healing process begins.

Summary

Findings were presented from an exploration of the lived experiences of women diagnosed with stage II or greater gynecological cancer. This chapter also identified shared experiences among the women in the study in addition to coping strategies. Data management and analysis processes were summarized. Five themes were identified: the existential experience of time, awareness of loss, navigating new waters, sustaining faith, and moving forward. Twelve subthemes reflected the salient specific elements of each theme. Participant quotes provided rich data to support identified themes and subthemes. Finally, this chapter
presented the meaning of the lived experiences of women diagnosed with late stage gynecological cancer through an intimate sharing of their stories of change, transition, and adaptation.
CHAPTER 5
DATA SYNTHESIS, CONCLUSIONS, RECOMMENDATIONS

Data synthesis, which includes addressing the research questions, is the focus of this chapter. The significance of the study is presented utilizing an interpretive phenomenological approach. Furthermore, the implications and recommendations for nursing practice and future research are described. In conclusion, the chapter presents the final reflections of this researcher pertaining to the study.

Data Synthesis

Previous studies related to women's experiences with gynecological cancer identified the unique physical and psychosocial stressors these women experience (Beeseley et al., 2008; Caldwell, 2003; Camperson, 2009; Chow, 2013; Fieler, 2007; Guenther et al., 2012; Holt et al., 2014; Howell et al., 2003; Jefferies & Clifford, 2011; Phillips-Salimi & Andrykowski, 2013; Rzek, 2011; Steele & Fitch, 2008). In addition, cancer-related stigma, late stage diagnosis, distinct experiences of isolation and loneliness, intense decisions related to treatment, extensive treatment regimens, and loss of reproductive capabilities were identified as primary stressors in this population (Abbott-Anderson, 2015; Abbott-Anderson & Kwekkeboom, 2011; Cataldo et al., 2011; Guenther et al., 2012; Howell et al., 2003; Jefferies & Clifford,
Poor survival rates, specifically in late stage ovarian, endometrial, and cervical cancer, were also recognized in this population (American Cancer Society, 2018; Beesley et al., 2010; Guenther et al., 2012; Howell et al., 2003; Jefferies & Clifford, 2011; Manne et al., 2014). The existing body of literature focused on identifying the physical and emotional stressors (Abbott-Anderson & Kwekkeboom, 2011; Steele & Fitch, 2008) and the quantification of the severity of physical and emotional stressors (Manne et al., 2014; Steele & Fitch, 2008). Furthermore, the existing studies often examined one type of gynecological cancer to the exclusion of others (Howell et al., 2003; Jefferies & Clifford, 2011). It was important to understand if these experiences were shared across the spectrum of gynecological cancers. Understanding shared experiences of women diagnosed with stage II or greater gynecological cancer guided the development of the four research questions.

Through this study, the participants depicted a more comprehensive perspective of the cancer experience than previous research. This study integrated the physical and emotional experiences of these women from pre-diagnosis to survivorship. Furthermore, the study identified the significant coping strategies of faith and resiliency.

Research question one for this study aimed to understand the lived experiences of women diagnosed with stage II or greater gynecological cancer. When participants were asked to describe what their life was like before their cancer diagnosis and after their cancer diagnosis, many participants discerned a
difference in their life experiences before cancer and after cancer. These changes included a shift in *physical and emotional experiences, perceptions of the future, an awareness of loss, and sustained faith.*

Many of the women described their experiences with cancer in timeframes of pre-diagnosis, treatment, and post-treatment. The patient’s age at diagnosis often impacted the individual’s current perception of the future, in addition to their perceived understanding and awareness of loss. Furthermore, almost all of the women described an expanded faith during their experience with cancer, while also finding meaning in their experience.

Furthermore, the prominent theme of sustaining faith, specifically belief in a higher power and purpose in the experience, was a prevalent theme not previously distinguished in earlier studies. This was a key coping strategy for a majority of the women in this study. Faith became the key pillar for adaptation and resiliency when the women faced cancer.

The unique physical and psychosocial experiences the women in this study encountered when diagnosed with late stage gynecological cancer were consistent with the literature. For example diagnostic delay, supportive care needs, and feelings of aloneness were consistent with previous studies (Beesley et al., 2008; Guenther, 2008; Guenther et al., 2012; Holt et al., 2014; Howell et al., 2014; Jefferies & Clifford, 2011; Steele & Fitch, 2008; Vandborg et al., 2012). Guenther (2008) also acknowledged varying emotional experiences that coincided with the pre-diagnosis, concurrent with treatment, and post-treatment timeframes. In addition, this study was consistent with Rezk’s (2011) study, which identified both short-term and long-
term impacts on quality of life and physical function following treatment for gynecological cancer.

Other findings that were consistent with the literature included identification of areas of distress and loss identified by gynecological cancer survivors. In a study conducted by Beesley et al. (2008), which included 802 gynecological cancer patients, women reported concerns of worry about those close to them and uncertainty about the future as major areas of distress. These two areas of distress ranked in the top three areas of unmet needs for gynecological cancer survivors (Beesley et al., 2008). In addition, Caldwell's (2003) study on sexuality and body image in gynecological cancer survivors, noted both a shift in self-identity and loss of maternal opportunities by study participants. Jeffries & Clifford (2012) discovered psychological and sociological shifts that occurred in young women diagnosed with cancer of the vulva. These findings by Jeffries & Clifford (2012) where a psychosocial shift occurs due to a physiological change in the environment speaks to Roy's adaptation model (2009) and the health-illness transition, including feelings of aloneness and a sense that everything has changed since diagnosis.

A more rich understanding of the awareness of loss and shift in the perception of the future that women experience with advanced gynecological cancer occurred through this study. While previous studies focused on the loss of physical function, the women reported their most significant loss as future time with family and friends. In addition, the women were able to provide insight into how self-identity transitions occur throughout the cancer process, from illness to survivorship, and how this transition can occur multiple times during this process.
Research question two aimed to understand the health-illness transitions that occur when women are diagnosed with late-stage gynecological cancer. As participants discussed their experiences being diagnosed with and treated for gynecological cancer, some women noted an immediate shift in their perspective from being a well person to being a person diagnosed with cancer (Meleis, 2010; Shumacher & Meleis, 1994). For some women this perceived shift happened gradually over time or before their diagnosis even occurred. The health-illness transition pertained to both emotional and physical changes the women experienced during this period.

Participants consistently identified how they adapted to the stress associated with their cancer diagnosis. The individual’s understanding of stress and their response to said stress often resulted in increased resiliency and an acceptance of “the new normal.” This is consistent with Roy’s adaptation model that an individual is consistently interacting with his/her environment and changes in the environment will subsequently influence the behavior of the individual (Roy, 2009). In this case, women who were diagnosed with the environmental stimuli/stressor of cancer adapted to this change and were able to reflect on the positive impact it had on their life.

A key finding of this study came from the integration of the conceptual framework of Meleis’ transitions theory and Roy’s adaptation model. While Roy’s adaptation model focuses on the adaptive and coping ability of the individual when a stressor occurs, Meleis’ transitions theory focuses on the subjective meaning in the experience when the stress occurs. Finding meaning in the experience allows the
individual to adapt to future stressors with different coping strategies than they might have had before. The integration of the conceptual framework provided insight into the adaptation to the environmental stimuli/stressor of cancer (Roy’s Adaptation Model), but also provided insight into the coping strategies, such as faith and meaning in the cancer experience (Meleis’ transitions theory).

Through this study, women were able to articulate their cancer experience from pre-diagnosis to survivorship. This study did not compartmentalize the cancer experience into one component of the experience such as physical and emotional symptoms or pre-diagnosis and survivorship. Inviting the women to give voice to the entirety of the cancer experience, while including all cancer types in the study, provided evidentiary support of the experiences that are shared across the gynecological cancer types. A holistic picture of the women’s journey was complete.

The health-illness transition as it relates to late stage gynecological cancer was a significant finding of this study. Furthermore, the application of Roy’s adaptation model to Meleis’ transitions theory provided new insight into women's experiences with advanced stage gynecological cancer, specifically as it relates to the transition timeframes of pre-diagnosis, treatment, and post-treatment. A comprehensive picture was painted of the women’s personal perception of health and illness through the telling of their stories.

Finally, the key concept of resiliency and the shift in the perception of “normal” in gynecological cancer survivors was recognized through this study. Resiliency was a key concept identified in Camperson’s (2009) study on emotional experiences with gynecology oncology. Camperson defined resiliency as positive
adaptation in spite of hardship. The women in this study echoed the sentiments of the participants in Camperson’s (2009) study where adaptation and survivorship at all costs is what is important.

The perception of stigma associated with a late stage gynecological cancer diagnosis was the focus for the third research question. For the purpose of the this study, Cataldo and colleagues’ (2011) definition of health-related stigma was used to recognize both internal and external stigmatizations experienced by women diagnosed with late stage gynecological cancer. Many women in the study identified an “internalized sense of inferiority or shame” they associated with losing their hair to chemotherapy treatments and being bald (Goffman, 1963; Lebel et al. 2013; Lebel & Divens, 2008, p. 717). External stigmatization also resulted from physical alterations in the individual’s appearance during the treatment process. These physical deformities can be temporary or permanent, like baldness, but can result in decreased socialization due to felt or enacted stigmas (Bonanno & Esmaeli, 2012; Lebel et al., 2013).

Shifts in the physical appearance of the women in this study resulted in emotional vulnerability unlike the women had ever known. The women identified being bald as an outward sign of their internal illness and emotional struggle. Being bald became a way in which their emotional battle wounds became public. For some women, the moment their hair was no longer present was the moment the cancer experience became real.

A shift in the concept of self was also was associated with the stigma of cancer. Several women reported how their societal or occupational role shifted
because of their diagnosis with cancer and evident treatment effects. In some cases, the women would try to mask their diagnosis or treatment effects in order to avoid being characterized as different, ill, or needing help. For these women, if they did not acknowledge or accept these shifts to the outside world, it lessened the blow of the cancer experience.

This study provided insight into the personal meaning the women attributed to experiencing internal and external stigmas when diagnosed with and treated for late stage gynecological cancer. A significant and unique finding of this study was the recognition of the shared stigmatization experiences women had across varying gynecological cancer types and the steps these women would take to reduce being characterized as ill. Furthermore, this study distinctly uncovered the spectrum of experiences that resulted in both internal and external stigmatization in this population of women, for example hair loss associated with chemotherapy treatments, wearing hats to cover baldness, associated shame, and feeling vulnerable. Furthermore, it brought to light the varying ways the women would cope and rationalize when encountering these stigmatizations.

Finally, research question four aimed to identify what daily behaviors of the women were influenced by the environmental stressor of cancer. Several of the women reported significant physical symptoms leading up to their cancer diagnosis and during the treatment process which impacted their ability to function, such as weight gain and mobility. In some cases, women continued to experience substantial physical symptoms despite completing their treatment regimen. These physical effects included fatigue, bladder impairment, frequent urinary tract
infections, and peripheral neuropathies. These long-term impairments were consistent with previous studies of gynecological cancer survivors (Jefferies & Clifford, 2012; Rezk, 2011).

Likewise, women described the emotional impact their diagnosis with and treatment for late stage gynecological cancer had on them. For many women this emotional impact resulted in a shift in their concept of self and an awareness of limited time with family and friends. For example, participants reflected on their inability to participate in events during their treatment and future milestones with their family upon their death. This awareness of loss reflects a transition that occurs during the cancer diagnosis and treatment process. In many cases, this health-illness transition resulted in new found strength and an understanding of what everyday life would be like moving forward.

These collective experiences noted by the women directly related to the conceptual framework of Meleis’ transitions theory and Roy’s adaptation model utilized to develop the study. A key outcome of this study was a clearer understanding of the spectrum of the total experience of cancer from diagnosis to survivorship. Furthermore, this was where shared experiences could be identified across gynecological cancer types.

Each of the women in the study described the lasting impression the health care provider experience had on the diagnosis and treatment process. The health care provider experience provided an additional piece of the puzzle, which provided the complete picture of the cancer diagnosis and treatment process. Poor communication by health care providers often influenced the participant's view of
care. These experiences were consistent with the literature, which recognized the need for improved relationships and communication with health care providers when women are diagnosed with advanced stage gynecological cancer and throughout their treatment process (Camperson, 2009; Fieler, 2007; Kinney, 2006).

Diagnostic delay and negative health care provider experiences were also frequently associated with the primary care provider's lack of knowledge or dismissal of gynecological cancer symptoms. Diagnostic delay often occurs in gynecological cancer, leading to advanced stage cancer and poorer prognosis at the time of diagnosis (Fieler, 2007; Guenther, 2008). The delay is often associated with non-specific symptom presentation, unrecognized symptoms of gynecological cancer by the primary health care provider, and delay in referrals to specialists (Fieler, 2007; Guenther, 2008; Vandborg et al., 2012). In a study conducted by Vandborg et al. (2012), there was a median delay of 101 days identified in 161 gynecological cancer patients. In 10% of cases, the delay was greater than 436 days (Vandborg et al., 2012). Findings in the literature were consistent with the delay in diagnosis reported by the women in this study.

In contrast to these negative health care provider experiences, several women recognized the lasting impression positive health care provider experiences had on them. Throughout a majority of the interviews, women often associated their positive health care provider experiences with relationships they developed or interactions they had with oncology physicians or nurses. The lasting impact these health care provider experiences had on every woman in the study affirmed the significance of the patient/health care provider relationship during the cancer
diagnosis and treatment process. Negative health care provider experiences illustrated the importance of enhanced knowledge and training about the signs and symptoms of gynecological cancer and the necessity of communication, both by health care providers and between health care providers during the diagnosis and treatment process. Likewise, positive health care provider experiences highlighted the substantial impact nurses have on patients, specifically oncology nurses. Nearly every participant identified a specific occasion where an interaction with a nurse made a lasting impression on her.

Limitations
An identified limitation of this study included the potential for attrition with study participants. Due to the poor prognoses and limited survival rates of women diagnosed with gynecological cancer, attrition did occur. Specifically, an individual was identified as eligible to participate in the study by phone, but later was not physically well enough to participate in the interview due to complications of the illness and treatment process. Geographical limitations did occur, as study participants were primarily receiving treatment at a hospital in the Midwestern United States, therefore, the transferability of the findings may be limited (Polit & Beck, 2012; Streubert & Carpenter, 2011).

The timeframe for the IRB approval and data collection process for this study occurred over two years. This timeframe was prolonged due to the constraints of the hospital and number of patients who self-identified for inclusion in the study. These limitations led to an extended period of time from study initiation to
completion. Finally, an additional limitation is that I am a novice researcher, although an experienced researcher guided me throughout this process.

Implications and Recommendations for Nursing Practice

Contributions from this research include findings that illuminate the spectrum of the health-illness transition women experience when diagnosed with advanced stage gynecological cancer. Specifically this research promotes understanding of the personal perception and impact of the diagnosis of cancer, adaptation to the environmental stressor of cancer, and discovering meaning in the experience and its impact on survivorship. In addition, the research findings expanded what was known from previous studies and provided poignant descriptions of shared experiences of internal and external stigmatization women encountered with advanced cancer diagnoses and treatment processes. Study results provide insight into the shared experiences of the physical and emotional experiences of cancer, recognition of loss, strengthened faith and purpose, and changed perspectives of the future. Finally, this study reveals the shared coping strategies of the women, like faith and resiliency, while acknowledging and embracing the personal transformation the women experienced throughout this cancer journey.

This research highlighted the importance of communication by the health care provider throughout the patient’s cancer journey, and clarified the critical importance and impact of the nurse’s relationship with the patient during this process. Other implications for practice include improving knowledge of the physical and emotional changes these women experience throughout this process,
in addition to recognizing the losses the women encounter and the modes of adaptation they utilize.

**Implications and Recommendations for Future Research**

Findings within this research mirror other studies related to unique physical and psychosocial stressors women experience when diagnosed with and treated for gynecological cancer. Furthermore, these findings illuminated how these unique physical and psychosocial symptoms are intertwined and influence patients’ perception of time and quality of life. Common shared experiences among women diagnosed with advanced stage ovarian, endometrial, and vaginal cancer included the health/illness shift, stigmatization, and resiliency. While there were some differences identified in the experiences of older and younger women in the study, due to the limited number of women enrolled in the study under the age of forty, future studies are warranted to further understand women’s experiences of being diagnosed with late stage gynecological cancer prior to the age of 40.

The findings further revealed the significance of the health-illness transition and cancer-related stigma that occurs in this population of women and this study can provide the framework for future research in these areas. Further studies are needed to consider the magnitude of both personally driven (internal) and societally/culturally driven (external) cancer-related stigmas. In addition, a noticeable shift in the health/illness spectrum occurred for most women in the study, but additional studies may be warranted to understand why the shift occurs earlier versus later and suddenly versus gradually for certain gynecological cancer patients.
Researcher’s Final Reflections

Within this study, women diagnosed with late stage gynecological cancer provided rich, thick descriptions of the lived experience of an advanced gynecological cancer diagnosis. As I reflected on the participants’ narratives, my understanding of how the unique physical and psychosocial stressors of late stage gynecological cancer are intertwined and influence patients’ quality of life was improved. Likewise, this study unveiled shared experiences among women diagnosed with stage II or greater gynecological cancer.

A key finding of this study, which extended from the conceptual framework of the study, was new insight into the spectrum of the experience of cancer. Through the application of Roy’s adaptation theory, significant components of the environmental stressor of cancer, such as physical symptoms, emotional experiences, and associated losses, were identified. Through the application of Meleis’ transitions theory, an acknowledgement of the purpose in the cancer experience, recognition of new coping strategies, such as resiliency and faith, and strengthened survivorship occurred.

Assumptions included in this study were supported by the research findings, including the health-illness transition and the occurrence of adaptation throughout the cancer diagnosis and treatment process. However, the melding of the conceptual framework of Roy and Meleis provided new insight into the spectrum of cancer from illness to survivorship and finding purpose and meaning in the experience.
As women described their experiences with gynecological cancer, I was surprised to discover the significance these women placed on faith throughout this time period. While spirituality was a theme in Camperson’s (2009) study on women’s emotional experiences with gynecological cancer, faith was not a prominent theme in the literature review, but became heavily emphasized during the interview process. In addition, a number of women described feelings of relief with diagnosis, which was also not evident in the previous literature.

While I assumed women would be willing to be transparent and divulge their emotionally complex experiences of being diagnosed with late stage gynecological cancer, their vulnerability throughout the interview process astounded even me. No participant included in the study requested to discontinue the interview or refused to answer a question. Instead they provided poignant reflections on their experience in a sincere and honest manner. At times they became emotional, but always composed themselves and proceeded with the interview.

In addition to the emotions experienced by the participants in this study, I was caught off-guard by the extent of the emotional impact the participant interviews would have on me. While it was not difficult for me to maintain my composure in the interview process due to my training as a psychiatric-mental health nurse practitioner, I did find myself reflecting and processing the significance of these emotional encounters long after the interviews ended. Through my training and practice as an oncology nurse, I often empathized with the women’s experiences from a health care provider and treatment perspective.
In considering modifications I would make to this study upon its completion, I identified one change. Anecdotal information provided by the gynecologic-oncologist in the clinic was the difficulty of including late stage cervical cancer patients in the study due to lack of referrals for this cancer type to the clinic and the limited lifespan of cervical cancer patients that were referred to the clinic. One proposed modification for improving the number of participants and variety of cancer types included in the study would be to use active recruitment strategies, such as face-to-face recruitment in the outpatient clinic, chemotherapy and radiation treatment areas, and hospital cancer support groups. In addition, online blogs or electronic solicitation from social media sites may also improve participant recruitment and provide a broader population from multiple areas of the country.

This research contributes to the current body of knowledge of the lived experiences of women diagnosed with stage II or greater gynecological cancer. Findings illuminate the significance of the health-illness transition and the concepts of adaptation and stigmatization that occur in women with advanced stage gynecological cancer. A distinct discovery of this study was the theme of faith and its role in coping. Other unique findings of this study include the shared experiences of women diagnosed with late stage cancer across gynecological cancer types, staging (II – IV), and age at diagnosis.

Summary

This research promotes understanding of the personal perception and impact of the diagnosis of cancer, adaptation to the environmental stressor of cancer, and discovering meaning in the cancer experience and its impact on
survivorship. This chapter provided a synthesis of the data, while understanding the significance of the data utilizing an interpretive phenomenological approach to explore meaning of the experience for the participants. Limitations have been presented, and implications and recommendations for nursing practice and future research were delineated. This chapter concluded with my final reflections of this study and the experiences interviewing these exceptionally strong women.
REFERENCES


APPENDICES
IRB approval was secured from the hospital where the study was conducted. However, in order to protect the confidentiality of the site and participants, a copy of that approval form is not included in this appendix.
Tuesday, August 15, 2017

Ms. Stacey M. Meyers
Top of Organizational Structure
Atlanta, GA 30341

RE: The Lived Experiences of Women Diagnosed with Stage II or Greater Gynecological Cancer (H1707198)

Dear Ms. Meyers:

On behalf of Mercer University’s Institutional Review Board for Human Subjects Research, your application submitted on 14-Aug-2017 for the above referenced protocol was reviewed in accordance with Federal Regulations 21 CFR 56.110(b) and 45 CFR 46.110(b) (for expedited review) and was approved under category(ies) 6, 7 per 36 CFR 60364.

Your application was approved for one year of study on 15-Aug-2017. The protocol expires on 14-Aug-2018. If the study continues beyond one year, it must be re-evaluated by the IRB Committee.

**Item(s) Approved:**
This proposed interpretive phenomenological research study will focus on the lived experiences of women diagnosed with stage II or greater ovarian, uterine, and endometrial cancer; specifically, it will explore the individual's perspective related to quality of life, personal perceptions of cancer-related stigma, and the health-illness transition.

**NOTE:** Please report to the committee when the protocol is initiated. Report to the Committee immediately any changes in the protocol or consent form and ALL accidents, injuries, and serious or unexpected adverse events that occur to your subjects as a result of this study.

We at the IRB and the Office of Research Compliance are dedicated to providing the best service to our research community. As one of our investigators, we value your feedback and ask that you please take a moment to complete our Satisfaction Survey and help us to improve the quality of our service.

It has been a pleasure working with you and we wish you much success with your project! If you need any further assistance, please feel free to contact our office.

Respectfully,

[Signature]

Ava Chambliss-Richardson, Ph.D., CIP, CIM.
Associate Director of Human Research Protection Programs (HRPP)
Member
Institutional Review Board

*Mercer University has adopted and agrees to conduct its clinical research studies in accordance with the International Conference on Harmonization’s (ICH) Guidelines for Good Clinical Practice.*

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Mercer University IRB & Office of Research Compliance
Phone: 478-301-4101 | Email: ORC_Mercer@Mercer.edu | Fax: 478-301-2329
1501 Mercer University Drive, Macon, Georgia 31207-0001
APPENDIX B

PARTICIPANT FLYER
Participants Needed!

Please participate in a *doctoral research study designed to explore the lived experiences of women diagnosed with gynecological cancer, specifically ovarian, uterine, and endometrial cancer. Your personal experiences are needed to provide insight into the initial experience of being diagnosed with gynecological cancer and will provide valuable information. If chosen to participate, you will be asked to participate in a 60 to 90 minute interview. This interview session will be audiotaped. Personal information will not be included in the transcription of the audio recording. The interview will take place by phone or in a conference room at a cancer center.

Please contact Stacey M. Meyers
(Stacey.M.Meyers-Prosyniuk@live.mercer.edu or cell 517-403-5900)
for further information and to register as a participant in the study.

*Doctoral Research Study*

The Lived Experiences of Women Diagnosed with Stage II or Greater Gynecological Cancer

**Participation is confidential and voluntary**
An informed consent form was secured from the hospital where the study was conducted. However, in order to protect the confidentiality of the site and participants, a copy of that consent form is not included in this appendix.
Informed Consent
The Lived Experiences of Women Diagnosed with Stage II or Greater Gynecological Cancer

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators
Stacey Meyers, MSN, RN, APRN, PMHNP-BC is a doctoral student within the Georgia Baptist College of Nursing of Mercer University PhD in nursing degree program. Dr. Susan S. Gunby is the faculty advisor and doctoral committee chairperson. Contact information is provided below:

- Stacey.M.Meyers-Prosgnak@live.mercer.edu, Cell 517-463-5900
- Dr. Susan S. Gunby, SSGunby3@Mercer.edu, Office 678-547-6773, 3001 Mercer University Drive, Atlanta, Georgia 30341.

Purpose of the Research
This proposed interpretive phenomenological research study will focus on the lived experiences of women diagnosed with stage II or greater ovarian, uterine, and endometrial cancer. This study will explore the concepts of quality of life, personal perception of cancer-related stigma, and the health-illness transition.

The data generated from this research will be utilized to provide greater insight into the lived experiences of women diagnosed with stage II or greater gynecological cancer. Results may provide important information to identify shared lived experiences across the gynecological cancer spectrum. The researcher will utilize research findings for future scholarly endeavors, including presentations at professional conferences, publications, and as the basis for further research in this area.

Procedures
If you choose to volunteer for participation in this study, you will be asked to participate in one interview session. The session may be completed by phone or through a face-to-face interview while you are scheduled for an appointment at a university hospital clinic. The interview will be scheduled at a time that is convenient for you. Questions included in the interview session will

Mercer University IRB
Approval Date: 08/14/2017
Protocol Expiration Date: 08/13/2018
focus on your lived experiences of being diagnosed with gynecological cancer. The researcher will also ask you to provide demographic information, such as your age, ethnicity, marital status, living arrangements, work-related responsibilities, and cancer diagnosis. The interview will last approximately 60 to 90 minutes.

Potential Risks or Discomforts
There are no foreseeable risks associated with this study. Participants may encounter familiar positive or negative feelings as they reflect on their previous diagnosis of cancer. These feelings may cause discomfort or emotional reactions. You may request to discontinue the interview at any time and discontinue your participation from the study. You may also choose to remove yourself from the interview and return at a later time. No costs are associated with participating in this study.

Potential Benefits of the Research
There are no foreseeable benefits of participating in the study. However, study findings may benefit future practices in nursing and encourage further research on the shared, lived experiences of gynecological cancer patients.

Confidentiality and Data Storage
In order to protect the confidentiality of information shared by participants, your name and the names and exact locations of hospitals will not be specified in the dissertation. To protect confidentiality and promote honest replies from participants regarding their shared, lived experiences of being diagnosed with gynecological cancer, hospital names will not be utilized. As a participant, you will be instructed that your name will not be recorded on any of the transcripts and you will be advised to not mention your identifying information during the interview. Should a name or other identifying information be mentioned, the information will be removed and random letters will be assigned, such as YCG or STH. Additionally, the investigator will not be written notes during the interview. These notes will not contain names of any individuals or additional identifying information mentioned during the interview.

Confidentiality of participants will be protected through the self-selection of pseudonyms to represent their names on demographic forms. The participant-selected pseudonym will correspond with the pseudonym noted in the transcribed data. Only the principal investigator and dissertation chair will have access to digital recordings. The principal investigator and the chair of the dissertation committee will be the only individuals with access to demographic forms. Any names of persons or hospitals mentioned by participants will be redacted and replaced with pseudonyms (for persons) or non-identifying initials (for hospitals).

Digital recordings will be destroyed at the conclusion of the research process. Original documents with identifying information will be stored within a locked file cabinet at the researcher's home office for three years and then destroyed. However, interview transcripts will be kept indefinitely within the investigator's home office and will not contain any identifying information. The results
of this study will be utilized by the researcher for future scholarly endeavors. Participants' identities will never be shared or published.

Participation and Withdrawal
Your participation in this research study is voluntary. As a participant, you may refuse to participate at any time. To withdraw from the study, please contact Stacey Meyers by email at Stacey.M.Meyers-Prosnick@live.mercer.edu or cell 517-403-5900. You may also contact the investigator advisor, Dr. Susan Gunby, Gunby_SS@Mercer.edu or office 678-547-6773. Note: If the data are anonymous, subjects cannot withdraw after data collection has taken place.

Questions about the Research
If you have any questions about the research, please speak with Stacey Meyers at Stacey.M.Meyers-Prosnick@live.mercer.edu or cell 517-403-5900. You may also contact the investigator advisor, Dr. Susan Gunby, Gunby_SS@Mercer.edu or office 678-547-6773.

Audio or Video Taping
The interview will be digitally recorded for verbatim transcription. Your name or university hospital will not be included on the digital recording.

Reasons for Exclusion from this Study
If you are unable to read, write, or understand English and have not been diagnosed with gynecological cancer (stage II or greater disease state) in the past, then you are excluded from this study.

This project was reviewed and approved by Mercer University's Institutional Review Board. If you believe there is any infringement upon your rights as a research subject, then you may contact the Institutional Review Board, at 478-301-4101 or email at ORC@research.mercer.edu.

You have been given the opportunity to ask questions and these have been answered to your satisfaction. Your signature below indicates your voluntary agreement to participate in this research study.

Participant's Name (Print)                                           Date

Participant's Name (Signature)                                      

Person Obtaining Consent (Signature)                                

Mercer University IRB
Approval Date: 08/14/2017
Protocol Expiration Date: 08/13/2018
APPENDIX D

DEMOGRAPHIC FORM
Demographics and Clinical Factors Data Sheet

Pseudonym ____________________

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</tr>
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<td>Children</td>
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<td></td>
<td>Other</td>
</tr>
<tr>
<td></td>
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<td>Roommate</td>
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</thead>
<tbody>
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<td></td>
<td>Native Hawaiian or Pacific Islander</td>
</tr>
<tr>
<td></td>
<td>American Indian or Alaska Native</td>
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</tr>
<tr>
<td></td>
<td>Multi-Racial</td>
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<td>Disabled</td>
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<th>Occupation:</th>
<th>If working, where; position?</th>
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<table>
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<tr>
<th>Cancer Diagnosis:</th>
<th>Type of cancer:</th>
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<table>
<thead>
<tr>
<th>Cancer stage at the time of diagnosis:</th>
<th></th>
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</table>
APPENDIX E

INTERVIEW GUIDE
Interview Guide

1. Tell me about your experiences with cancer?
   a. Tell me about your life before your cancer diagnosis.
   b. Tell me about your life after your cancer diagnosis.

2. Tell me about the day that you were diagnosed.
   a. What made you seek healthcare?
   b. What do you remember about the day you were diagnosed?

3. Tell me about your experiences with your healthcare providers.
   a. Doctors
   b. Nurses
   c. Health care assistants

4. Tell me about the treatment measures you have chosen to undergo for your cancer.
   a. How did you come to choose the stated treatment measures?
   b. If you refused treatment, what made you choose to refuse treatment?

5. What stressors did you experience following your diagnosis and what stressors are you currently experiencing?
   a. For example: emotional, physical, financial, work, home, family
   b. How have you coped with these stressors?

6. What impact has your diagnosis had on your daily activities?

7. What impact has your diagnosis had upon the daily activities of your:
   a. Family
   b. Friends

8. Have you perceived anyone treating you differently following your cancer diagnosis? If “yes,” how do you perceive they treated you differently?

9. Have you ever felt characterized by or distinguished by your cancer diagnosis? If “yes,” please describe.
   a. Cancer-related stigma is defined as a real or perceived bias or discrimination that occurs because of a cancer diagnosis.

10. Tell me about how your quality of life has been impacted by your cancer diagnosis.

11. How does your diagnosis impact your perceptions of the future?
    a. What is your primary concern for your future, as it relates to your cancer diagnosis?
b. What is your primary concern for your family and friends’ future, as it relates to your cancer diagnosis?

12. What resources did you find to be (or would have been) beneficial throughout your cancer diagnosis and treatment process?

13. What other thoughts do you have regarding your experiences with your diagnosis and treatment process?