

WOMEN'S EMOTIONAL EXPERIENCES WITH
GYNECOLOGICAL ONCOLOGY

by

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Dedication

This dissertation is dedicated to my mother and father.

In Memory

This dissertation is in memory of my favorite gynecological patient, who died of complications of ovarian cancer in 2002, whom I'll refer to as "The Teacher." I wish she were alive today to read this work.

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ABSTRACT

WOMEN'S EMOTIONAL EXPERIENCES WITH GYNECOLOGICAL ONCOLOGY

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This study describes women's emotional experiences with gynecological oncology, with an emphasis on depression, using a qualitative phenomenology approach. The qualitative methodology was designed to give the women participants a voice.

Ten women who resided in North Texas participated in the study. Each of the women had been diagnosed with a gynecological oncology at some point in their lives. Seven of the women had an ovarian cancer diagnosis, one had cervical cancer, one had endometrial cancer, and one had a diagnosis of vaginal and cervical cancer. The participants ranged in age from 28 to 67 years of age.

The results of the data analysis revealed 11 themes for this group of women: *Wide Range of Emotions at Diagnosis, Advocacy, Support Groups, Personal Growth, Spirituality, Longevity, Complex Support Systems, Chemotherapy Side Effects, Bonded with Doctors, Medications, and Counseling.* The *Support Group* theme holds the key to many of these coping mechanisms as it appears to be a pathway to other themes. The women in the support groups appear to be key informants in developing information and ways to cope with gynecological cancers.

All of the participants endorsed three or more symptoms of depression after receiving their gynecological cancer diagnosis. The most commonly endorsed depression symptoms also happen to be side effects of chemotherapy and all the participants received chemotherapy. Of all of the participants, one, who was a minority, was significantly different from the other women in the study and reported significant distress and depression, which was alleviated by her support group involvement.

In this study, as I set out to study emotional experiences, I found resiliency was the key trait shared by the women. Resiliency is the consistent “positive adaptation in the face of significant adversity or risk” (Masten & Reed, 2002, p .75). The following quote from one of the participants captured the spirit of the women in this study, “You know, as soon as I knew what I had, it’s time to fight it. Tell me how to fight it, and I will do everything in my power to fight it.”

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CHAPTER 1

INTRODUCTION

Gynecological cancers are very prevalent in our society. Even so, the academic and medical communities continue to under-address this population with a lack of research. Only gynecological and breast cancers pertain mainly to women (few men have been diagnosed with breast cancer). With the advent and popularity of the Susan G. Komen Breast Cancer Foundation, not only was the stigma of having breast cancer lifted, but money for funding poured in and, with the emphasis on breast cancer needs, research flourished. However, while there has been substantial research addressing breast cancer, gynecological cancers have not been studied extensively. With gynecological cancer, there is still a social stigma and a lack of support from the general population, creating a lack of funding for research. In particular, there is a gap in the literature concerning gynecological cancers and women's emotional experiences and depression.

My interest in the gynecological oncology population evolved because I was a gynecological oncology social worker for many years at a large hospital. I was curious why some women had more or less distress and/or depression than other women. Some women I followed for many years. I watched them go through surgeries, chemotherapy, radiation treatments, bowel obstructions, and a wide variety of other medical complications. I visited with them after the doctor had given them their cancer

diagnosis, and I wondered if somehow we could do it better. I saw a wide variety of reactions from anger to shock to confusion to acceptance. One of my favorite memories was working with a gravely ill gynecological oncology patient. I asked her what her favorite activity was, besides being with her family. She replied playing cards. So I got a deck of cards, and we played “Go Fish” for a while. Her daughter came in and greeted us. The phone rang and the daughter answered the phone. She said “No. My mom can’t come to the phone right now. She is busy playing cards with her social worker”. Days later she died. I had the rare opportunity to follow these patients for years and had the privilege to share their joys and sorrows. These experiences helped me select the topic of this paper.

Because of the emotional nature of receiving a cancer diagnosis and having to deal with a life-altering medical diagnosis that turns a person’s life upside down with surgeries, multiple chemotherapies, and internal radiation treatments, the studying of women with a gynecological oncology diagnosis is a worthwhile topic.

1.1 Cancer Statistics

When looking at the cancer statistics in America, the number of newly diagnosed individuals is staggering. In 2007, an estimated 1,444,920 people received a cancer diagnosis (The American Cancer Society 2008c). Of that group, 678,060 were women. Estimates say 559,650 cancer deaths occurred and of that number 270,100 were women.

The American Cancer Society (2008b) lists the probability of a woman developing cancer over the course of her lifetime (the probability statistics exclude

certain skin cancers and in situ cancers): From birth to 39 years of age, the probability of developing cancer is 1 in 49; from 40-59 years of age, the probability is 1 in 11; from 60-69, the probability is 1 in 9; from the age of 70 and older, the probability is 1 in 4; and from birth to death, the estimate is 1 in 3. Keeping these statistics in mind, cancer has the capability of affecting every woman's life in America and not just the participants in this study. Even if the woman goes a lifetime without a cancer diagnosis, there is a chance that one of her beloved friends, a co-worker, a church member, a neighbor or a relative will be diagnosed with cancer.

According to the American Cancer Society (2008c), an estimated 78,290 women in the United States received a gynecological cancer diagnosis for 2007. Of those newly diagnosed women's diagnoses: 11,150 were cervical cancer, 39,080 were uterine corpus cancer (also known as uterine or endometrial cancer), 22,430 were ovarian cancer, 3,490 were vulvar cancer and 2,140 were vaginal cancers and less common female genital cancers. An estimated 28,020 women died of gynecological cancers in 2007.

The Texas Cancer Registry (2008) tracks and reports all new cancer cases for the state of Texas. The Texas Cancer Registry estimated 95,310 Texans were diagnosed with cancer in 2007. Of that number, 46,032 were women. With regards to gynecological oncology statistics, the Texas Cancer Registry Web site only reports ovarian, cervical and corpus/uterus (endometrial) cancer diagnosis for gynecological oncology cases and does not include other gynecological oncology diagnoses, such as vulvar and vaginal cancers.

Per the Texas Cancer Registry, more than 5,218 Texas women received a gynecological oncology diagnosis last year. They estimated 1,554 women received an ovarian cancer diagnosis, 1,115 women received a cervical cancer diagnosis, and 2,549 women received a corpus/uterus cancer (uterine/endometrial cancer) diagnosis in 2007 in Texas. The State of Texas has 254 counties (NACo, 2008). The statistics for two North Texas counties will be discussed: Tarrant and Dallas counties. During 2007, (Texas Cancer Registry, 2008), 6,207 individuals in Tarrant County received a cancer diagnosis. Of that number, 3,051 were women. Of those, 71 received a cervical cancer diagnosis, 103 were diagnosed with ovarian cancer, and 170 women were diagnosed with corpus/uterine (endometrial) cancer. For Dallas County, 8,355 individuals were diagnosed with cancer in 2007. Of that number, 4,101 were women. Of those, 107 had cervical cancer, 134 ovarian cancer, and 225 corpus/uterine (endometrial) cancer. The TRC also estimated 387 women with cervical cancer and 876 women with ovarian cancer died in Texas in 2007.

1.2 Description of Cancer

In a dissertation on cancer/oncology, the basics regarding oncology must be addressed. Human bodies are made from cells (National Cancer Institute, 2007d). Cells form tissues and tissues form organs. New, healthy cells form and take the place of older cells on a continuous basis. Cancer occurs when abnormal cells divide and spread within the body. These impaired cells form tumors which can either be benign (non-cancerous) or malignant (cancerous). There are several main types of cancer:

Carcinoma is cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is cancer that begins in the bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukemia is cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the bloodstream. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system (National Cancer Institute, 2007a, p.1).

An individual's cancer is named according to where it begins in the body (National Cancer Institute, 2007c). If a woman's cancer begins in her ovaries and later moves to her lungs, it is always known as ovarian cancer and not lung cancer. Cancer is staged. Staging refers to the rate and degree of the cancer's spread from its origin. Staging is from 0-4 for some cancers, such as cervical cancer, and 1-4 for other cancers, such as ovarian. When an ovarian cancer remains in the ovaries, it is considered stage 1. When it starts moving to surrounding tissues and other major organs, it is described as stage 2, stage 3, or stage 4.

When a cancer moves to other tissues or organs, it is said to have metastasized (referred to as "mets" in the medical community). When a woman has ovarian cancer with lung "mets," this means her ovarian cancer has spread outside of her ovaries to her lung. The more a cancer has spread from its origin, the higher the staging number. Stage 4 is the most severe stage and means there are multiple cancerous locations in a woman's body.

The medical community has survival statistics based on a 5-year survival time frame (National Cancer Institute, 2007e). "Survival rates indicate the percentage of people with a certain type and stage of cancer who survive the disease for a specific

period of time after their diagnosis” (National Cancer Institute, 2007e, p. 1). According to the American Cancer Society (2008a),

The 5-year survival rate refers to the percentage of patients who live *at least 5 years* after their cancer is diagnosed. Five-year rates are used to produce a standard way of discussing prognosis. Of course, many people live much longer than 5 years. Five-year relative survival rates take into account that people will die of other causes...

For instance, the five-year survival rate for stage 1 ovarian cancer is 84.7% - 92.7% (American Cancer Society, 2008a). The range number varies depending on whether a cancer is in one ovary, both ovaries, or both ovaries along with fluid outside of the ovaries. Taking the 92.7% and rounding it off, 93 out of 100 women will be alive in five years after receiving this diagnosis. The five-year survival rate does not mean she will necessarily be cured, but it means she probably will be alive (with or without cancer) at the five-year mark. Based on medical evidence, if a woman does not use evidence-based treatments, such as surgery, radiation therapy and/or chemotherapy, her longevity can certainly be less. After treatment, if no cancer is found, the medical community says there is “no evidence of disease.” Outside the medical community, the term generally used to describe this diagnosis is “remission.”

Upon receiving a diagnosis of gynecological cancer women need to receive treatment. Treatments include surgery, chemotherapy, and/or radiation therapy (Santoso & Coleman, 2001). Per the Mayo Clinic (2007), surgeries are used for diagnosing, staging, complete tumor removal, debulking and symptom relief. Debulking surgery occurs when it is not possible to take out all the cancer, so the

gynecological oncology surgeon takes out as much as possible. Symptom relief surgery can mean fixing a bowel obstruction. Another common surgery is a hysterectomy. With a full hysterectomy, a woman can no longer have children and will need to contemplate going on hormone replacement therapy. “Many women have an emotionally difficult time after this surgery. A woman's view of her own sexuality may change, and she may feel an emotional loss because she is no longer able to have children” (National Cancer Institute, 2004d).

For some, such cancers require more than just surgery to treat/cure the cancer. Many women also undergo chemotherapy and/or radiation therapy (Santoso & Coleman, 2001). Both chemotherapy and radiation therapy have multiple physical side effects. A few of the more common side effects of chemotherapy are: “nausea and vomiting, loss of appetite, diarrhea, fatigue, numbness and tingling in hands or feet, headaches, hair loss, and darkening of the skin and fingernails.” (National Cancer Institute, 2004a). Some of the more common side effects of radiation therapy are “fatigue, loss of appetite, nausea, vomiting, urinary discomfort, diarrhea, and skin changes” and painful sex due to dryness, burning, and tightening of the vagina (National Cancer Institute, 2004c). Due to the variety of physical effects alone, it would seem plausible that these women would be likely candidates for depression.

1.3 Description of Depression

Due to the emotional nature of having a cancer diagnosis, the fact that these particular cancers deal with a sensitive area of the body, and treatments have side

effects that range from early menopause to infertility and sexual difficulties, it is only natural to wonder about their emotional experiences of receiving such a diagnosis.

The emotional experiences of the women in this study cannot be defined by depression alone. However, in the course of dealing with gynecological oncology and emotional issues, an area of great concern is depression and its effect and impact on their well-being.

The Epidemiologic Catchment Area Study (Robins & Regier, 1990) estimates 9.5% of the American population suffers from a depressive disorder at some point during their lifetime. Within this statistic, bipolar I and II disorders account for 1.3%, whereas major depression constitutes the largest percentage with 4.9%, and dysthymia includes 3.2%.

The DSM-IV-TR (American Psychiatric Association, 2000) describes major depression as a person having five or more of the following symptoms for two weeks or longer: a depressed mood, diminished interest in almost all activities, significant weight fluctuation, insomnia/hypersomnia, feelings of restlessness, fatigue, feelings of worthlessness or excessive guilt, diminished ability to concentrate, and/or recurrent thoughts of death or suicide. In addition, one of the five symptoms must include either a depressed mood or a diminished interest in almost all activities.

Women are twice as likely to have depression than men. The exact reason is unknown but hormonal changes and lifecycle events may be factors, such as "...menstrual cycle changes, pregnancy, miscarriage, postpartum period, pre-menopause, and menopause. Many women also face additional stressors such as

responsibilities both at work and home, single parenthood, and caring for children and for aging parents” (National Institute of Mental Health, 2007, p. 4).

The National Cancer Institute acknowledges the wide range of concerns that a diagnosis of cancer can bring to the patient and their loved ones. They report (2004b):

Depression is a comorbid, disabling syndrome that affects approximately 15% to 25% of cancer patients. Individuals and families who face a diagnosis of cancer will experience varying levels of stress and emotional upset. Fear of death, disruption of life plans, changes in body image and self-esteem, changes in social role and lifestyle, and financial and legal concerns are significant issues in the life of any person with cancer, yet serious depression is not experienced by everyone who is diagnosed with cancer.

According to Valentine (2003), studies on hospitalized cancer patients reveal a higher rate of depression of between 25% and 42%. “In cancer patients, identical symptoms may be caused or influenced by physical (e.g. tumor site, pain), psychological (e.g. stress, premorbid function, maturity), and social (e.g. finances, interpersonal relationships) factors.”

Suicide is another element of depression. According to the National Cancer Institute (2007b), depressed cancer patients are ten times more likely to commit suicide than the general population. Cancer patients usually commit suicide at home with an overdose of their pain medications and sedatives. It is believed that many suicides among cancer patients go undetected and are therefore underestimated and under-reported.

1.4 Statement of the Problem

Women in America continue to be diagnosed with gynecological cancers. If the National Cancer Institute's estimates of depressed cancer patients are correct, of the 5,218 newly diagnosed ovarian and cervical cancer patients in Texas during 2007, 782 to 1,304 (15% to 25%) will have depression and psychological distress. Since this estimate does not include other gynecological cancers, such as vaginal, vulvar, endometrial and trophoblastic cancers, the number could well be much higher within this population. While much of the research has been quantitative, qualitative research is needed to give these women a voice. Due to the lack of attention and research from the medical and educational communities, this area needs more exploration.

1.5 Importance to Social Work

Research into this issue is important to the social work community for a number of reasons. Social workers are a vital part of the medical community. They are employed in the medical community to address cancer patients' specific needs and concerns, whether it is facilitating communication with the physician, obtaining home care after surgery, sharing financial resources, or educating patients and their families about support groups to help them through their difficult journey. Social workers who are clinical social workers are also trained therapists and are able to provide therapy to cancer patients. The National Institute of Mental Health (NIMH) acknowledges that clinical social workers are important to this population. NIMH writes, "Treatment for depression in the context of cancer should be managed by a mental health professional—for example, a psychiatrist, psychologist, or clinical social worker—who is in close

communication with the physician providing the cancer treatment” (2002, p. 3).

The more information that can be gathered on the depression issue, the better social workers will be able to educate and assist patients. By working closely with the medical staff, social workers have the ability to influence doctors and nurses and to educate the medical staff to better serve their gynecological oncology population. With more information on this topic, social workers can take this information to further advocate in the areas of patient issues, funding and additional research.

In addition, most hospital social workers have master’s degrees and are more than capable of performing psychosocial assessments, screening for depression, and of course assisting with helpful and pertinent resources. Medical facilities need to acknowledge the needs of the newly diagnosed women, the vital role of the medical social worker, and to come together for a more proactive rather than a reactive stance to help women get through their gynecological oncology experience.

Unfortunately, many women in the U.S. are being underserved particularly by the medical community. When a women receives a gynecological oncology diagnosis she should also receive a psychosocial assessment by a social worker to determine any needs and to determine what interventions are warranted to help the patient. This is not always the case. It should be mandatory at all hospitals, outpatient clinics, and doctors offices that all newly diagnosed gynecological oncology patients get a psychosocial needs assessment and a comprehensive cancer patient planner with a wide variety of resources in it for current and future needs. There is much that can be done to help gynecological cancer patients. The goal of this study is to help shed light on this issue

to benefit future gynecological oncology patients.

1.6 Purpose of the Study

The design scope of this study is to retrospectively explore the emotional experiences of women with a diagnosis of gynecological oncology, who received chemotherapy, using the phenomenology approach and guided by the biopsychosocial model to identify themes. The emotional experiences of those without depression and with depression would be compared, if they exist. The emotional experiences of those without depression symptoms and those with depression symptoms would be compared, if they exist. Any cultural differences would be compared if they exist. The study also looks at the implications for social work practice, policy, and research.

The following chapter discusses the empirical research literature on gynecological oncology and depression. The methods and findings of the studies will be addressed.

CHAPTER 2

LITERATURE REVIEW

This chapter reviews the empirical literature related to gynecological oncology and women's emotional experiences with depression and psychological distress. The literature review is important and necessary to reveal what studies have been done thus far on the topic. The methods and finding of the studies will be addressed.

2.1 Methods for Empirical Review

This literature review will examine studies related to gynecological oncology and emotional experiences, with an emphasis on depression in the United States. A variety of Internet search engines and sources were used to obtain the studies: Medline; CINAHL; PsycINFO; National Cancer Institute; the National Institute of Mental Health, Pro-Quest; Wiley Inter Science; Springer Link; EBSCOt; and Science Direct. Non-profit organizations, bibliographies, the University of Texas at Arlington's library catalog, government Web sites, and the World Wide Web were also searched for supportive information and links to pertinent published studies. The key search words were women, depression, cancer, ovarian, cervical, oncology, gynecological, gynecological oncology, mood, psychosocial, anxiety, mental health, psychological, and distress. No specific range of years was specified in the literature search due to the small amount of existing research available on this topic. The studies included women

with any type of gynecological diagnosis. Studies done on women who are “at risk” of being diagnosed with a gynecological cancer in the future were not included in this literature review, nor were studies regarding women being “screened” for gynecological oncology diagnosis.

Even though depression is the main emotional topic for this gynecological oncology literature review, actual depression studies related to gynecological cancers are few. That being said, other gynecological oncology studies involving psychological distress, mood, and quality of life were included in this literature review.

2.2 Methodological Concerns

This analysis of the literature included a wide range of variability with the types of cancer and stages of cancers, as some studies just used ovarian cancer patients in their samples and others included a wide variety of gynecological oncology diagnoses. Stage of treatment varied as some used recently diagnosed individuals and other studies included survivors. The studies also examined a variety of treatment types with the focus being on any treatment, versus chemotherapy, versus radiation therapy. Some of the studies were completed in a short time period while others were longitudinal. Sample sizes differed as did the use of comparison groups. In addition, studies were sought where depression was one of the main topics of the study, but due to the limited research, other studies which addressed depression, anxiety, emotional distress, psychological distress, depression symptoms, and mood as a subsection were also chosen.

Due to the great deal of variability of these studies and their predominate use of

non-probability sampling, the generalizability of these studies is limited. The studies do, however, give insight into this area of study and allow an overview of factors that play a role in depression. After extensive search, 20 studies are included in the literature review. A chart describing key aspects of the studies is located in Appendix A.

2.3 Description of Studies

The three types of research designs are exploratory, explanatory and descriptive (Rubin & Babbie, 2001). Of the 20 articles located for this research review, the majority were descriptive studies (Bodurka-Bevers et al, 2000; Bradley, Rose, Lutgendorf, Costanzo, & Anderson, 2006; Cain et al., 1983; Carter et al., 2005; Cerfolio, 1995; Ell et al., 2005; Evans et al., 1986; Kornblith et al., 1995; Lutgendorf et al., 2000; McCorkle, Tang, Greenwald, Holcombe, & Lavery, 2006; Meyerowitz, Formenti, & Ell, 2000; Miller, Pittman, Case, & McQuellon, 2002; Nail, King, & Johnson, 1986; Parker, Baile, de Moor, & Cohen, 2003; Roberts, Rossetti, Cone, and Cavanagh, 1992; Wenzel et al., 2002; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001), two were experimental (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 2006; Manne et al., 2007) and one was explanatory (Norton et al., 2005). Of the descriptive studies, four were descriptive comparative (Bradley et al., 2006; Lutgendorf et al., 2000; Miller et al., 2002; Roberts et al., 1992) and three were descriptive, longitudinal studies (Cerfolio, 1995; Kornblith et al., 1995; Nail, et al., 1986). Two of the studies were comparative longitudinal studies (Cain et al., 2006; Manne et al., 2007).

Two research studies (Cerfolio, 1995; Evans et al., 1986) involved a psychiatric liaison evaluation of hospitalized patients with the DSM-III/DSM-III-R criteria for a variety of mental health issues (such as depression, anxiety, and adjustment disorder). McCorkle, et al., (2006) study involved depression in cervical cancer survivors. Zabora et al., (2001) explored the psychological distress of newly diagnosed patients and Cain, et al., (1983) examined the psychological impact of being diagnosed with cancer. Norton, et al., (2005) was also interested in distress, along with support, self-esteem and control issues. One study (Carter et al., 2005) examined the impact of infertility issues due to cancer treatments. Two studies examined radiation therapy patients in regard to coping, mood (Nail et al., 1986) and depression (Meyerowitz et al., 2000). Ell et al., (2005) examined depression in low-income minority women. Some studies involved interventions. Manne et al., (2007) and Cain, et al., (2006) both examined the long-term effects of counseling interventions in reducing depression.

Four of the 20 articles (Kornblith et al., 1995; Miller et al., 2002; Roberts et al., 1992; Wenzel et al., 2002) dealt primarily with quality of life issues. Quality of life is defined by Bodurka-Bevers et al., (2000), as a “multidimensional construct that, at a minimum includes physical, functional, psychological, and social domains” (p 302). Roberts, et al., (1992) were concerned with quality of life for post-surgery survivors. Miller et al., (2002) and Wenzel et al., (2002) examined quality of life with survivors as well.

Others dealt with psychological issues and quality of life. Lutgendorf et al., (2000) was interested in mood and quality of life in chemotherapy patients. Bodurka-

Bevers et al., (2000) studied depression, anxiety and quality of life. Parker et al., (2003) dealt with psychosocial factors and quality of life. Bradley et al., (2006) examined the mental health of survivors and quality of life.

2.4 Sample Collection Methods

Interviews and surveys were the most widely used methods of obtaining the data. The majority of the studies used surveys (Bodurka-Bevers et al., 2000; Bradley et al., 2006; Carter et al., 2005; Lutgendorf, et al., 2000; Miller et al., 2002; Norton et al., 2005; Parker et al., 2003; Zabora et al., 2001). Some studies combined interviews and surveys (Cain et al., 2006; Ell, et al., 2005; Evans et al., 1986; Kornblith et al., 1995; Meyerowitz et al., 2000; McCorkle et al., 2006; Nail, et al., 1986; Roberts, et al., 1992; Wenzel et al., 2002). Three studies also used the subject's medical records (Bradley et al., 2006; Lutgendorf et al., 2000; Zabora et al., 2001). One study used interviews, medical records and staff input at the hospital (Cerfolio, 1995). Four studies combined quantitative and qualitative approaches (Carter et al., 2005; Meyerowitz et al., 2000; Roberts et al., 1992; Wenzel, et al., 2002).

Three of the longitudinal studies used interviews initially (Cerfolio, 1995; Kornblith et al., 1995; Nail et al., 1986) and follow up was done either in person, via phone or via mail. The two counseling intervention longitudinal studies used interviews, counseling sessions and surveys (Cain et al., 1983; Manne et al., 2007) with follow-up surveys (Manne, et al., 2007) or assessment interviews and surveys (Cain et al., 1983).

The studies used different surveys to measure depression. The Center for

Epidemiologic Studies-Depression (CES-D) was the most popular questionnaire to diagnose depression (Bodurka-Bervers, et al., 2000; Bradley et al., 2006; Cain et al., 1983; Carter et al., 2005; McCorkle et al., 2006; Meyerowitz et al., 2000; Parker et al., 2003; Wenzel et al., 2002). The CES-D is reported to have good reliability and validity.

The Beck Depression Inventory (BDI) was used to measure depression (Manne, et al., 2007) as was the Hamilton Depression Rating Scale (Cain et al., 1983; Cain et al., 2006; Evans, et al., 1986). The Carroll Rating Scale for Depression (Evans, et al., 1986) and the PHQ-9 (Ell, et al., 2005) were also used to measure depression. The PHQ-9 is reported to have good validity and reliability. The Hamilton Anxiety Scale was used to measure anxiety (Cain et al., 1983; Cain et al., 2006).

The Profile of Mood States (POMS) and the Mental Health Inventory (MHI) were utilized as well. Three of the studies used the Profile of Moods States (POMS) (Bradley et al., 2006; Lutgendorf et al., 2000; Nail et al., 1986). The POMS is used to identify mood. It has six subscales: depression, anxiety, anger, vigor, fatigue and confusion. The POMS is reported to have good reliability and validity.

The MHI was used to identify the subject's psychological state. It was used in two studies (Kornblith et al., 1995; Norton et al., 2005). The MHI has five subscales: depression, anxiety, general positive effect, emotional ties, and loss of behavioral or emotional control. The MHI reportedly has been normed.

Roberts et al., (1992) study used the SCL-90-R, which addressed psychological distress in medical patients. The SCL-90-R has nine indicators of distress: depression, anxiety, somatization, obsessiveness-compulsiveness, interpersonal sensitivity, hostility,

phobic anxiety, paranoid ideation, and psychoticism. This study did not address validity or reliability. However, the authors did say the measure had been normed on a healthy population.

Zabora et al., (2001) and Ell et al., (2005) used the Brief Symptom Inventory (BSI) to measure psychological distress. The BSI contains three global scales: global severity index, positive symptom distress index and the positive symptom total. Its nine subscales consist of depression, anxiety, phobic anxiety, obsessive-compulsive, psychoticism, paranoid ideation, hostility, somatization and interpersonal sensitivity.

Bodurka-Bervers et al., (2000) also used the FACT-O to measure quality of life, and it had an emotional well-being subscale and the Spielberger State Trait Anxiety Inventory Subscale. The FACT-O reports good validity and reliability and the State Anxiety Subscale has good internal consistency. Miller et al., (2002) and Lutgendorf et al. (2000) used the Functional Assessment of Cancer Therapy (FACT-G), which is a quality of life survey with an emotional well-being subscale. The FACT-G has good validity. Lutgendorf et al., (2000) also used the Coping Orientation to Problems Experienced (COPE) to assess coping and the Impact of Event Scale (IES) to assess coping styles. Carter et al., (2005) also used the IES. Both the COPE and IES reported good validity.

2.5 Sample Sizes

Gynecological oncology sample sizes varied for these studies. Four studies used sample sizes ranging from 20 to 32 subjects (Carter et al., 2005; Lutgendorf et al., 2000; Nail et al., 1986; Roberts et al., 1992), seven used samples between 49 to 85 subjects (Cain et al., 1983; Cain et al., 2006; Cerfolio, 1995; Evans et al., 1986; Meyerowitz et al., 2000; Miller et al., 2002; Wenzel et al., 2002), three studies had samples of more than 140 subjects (Bradley et al., 2006; Kornblith et al., 1995; Norton et al., 2005), two had between 200 to 246 subjects (Bodurka-Bevers et al., 2000; McCorkle et al., 2006). Four studies used sample sizes over 350 subjects (Parker et al., 2003; Manne et al., 2007; Ell et al., 2005; Zabora et al., 2001). Parker et al., (2003) had a total of 351 subjects for their sample of gynecological oncology, breast cancer, gastrointestinal, and urologic cancer patients. Of the 351 subjects, 60 % (n=210) were women and 17% (n=35) had a gynecological oncology diagnosis. Manne et al., (2007) also used a sample size of 353 subjects and all subjects had some type of gynecological cancer. Ell et al., (2005) had a sample size of 472 mixed cancer patients (gynecological cancers and breast cancer). Of that sample, almost half (n=222) of the patients had a gynecological cancer diagnosis. The largest sample was from the Zabora et al. (2001) study of 14 different types of cancers with a total of 4,496 subjects. Of the 4,496 subjects, 55% (n=2608) were women and 4.8% (n=216) had a gynecological cancer. All of the studies used nonprobability sampling.

Few studies used comparison groups (Miller et al., 2002; Roberts et al.

1992; Bradley et al., 2006; Cain et al., 2006; Lutgendorf et al., 2000; Manne et al., 2007). Roberts et al., (1992) compared 32 post surgery gynecological oncology survivors to 100 post surgery breast cancer patients. Lutgendorf et al., (2000) compared 24 advanced ovarian cancer patients undergoing chemotherapy to 24 early stage ovarian cancer patients without chemotherapy. Both Miller et al., (2002) and Bradley et al., (2006) compared an unequal number of gynecological oncology patients/survivors to an unequal number of healthy controls. Manne et al., (2007) and Cain et al., (2006) compared counseling intervention groups with control groups longitudinally

2.6 Statistical Analysis

All of the studies in the literature review used descriptive statistics. Four studies used qualitative data. Carter et al., (2005) and Wenzel et al., (2002) used themes. Roberts et al., (1992) and Meyerowitz et al., (2000) did not state their qualitative analysis.

One study used SEM or Structural Equation Modeling (Norton et al., 2005). One study used a growth curve analysis (Manne et al., 2007). Another study used nonparametric analysis (Evans et al., 1986). Most of the studies used some form of regression analysis (Bodurka-Bervers et al., 2000; Ell et al., 2005; Kornblith et al., 1995; Lutgendorf et al., 2000; McCorkle et al., 2006; Meyerowitz, et al., 2000; Miller et al., 2002; Parker et al., 2003; Zabora et al., 2001), bivariate analysis (Meyerowitz et al., 2000); ANOVA (Cain et al., 2006; Kornblith et al., 1995; Lutgendorf et al., 2000; Nail et al., 1986; Parker et al., 2003), one way ANOVA with linear contrasts (Cain et al.,

1983); MANOVA (Manne et al., 2007), correlations (Evans, et al., 1986; Lutgendorf et al., 2000; Miller et al., 2002; Nail et al., 1986; Parker et al., 2003; Wenzel et al., 2002), t-tests (Ell et al., 2005; McCorkle et al., 2006; Miller et al., 2002; Parker et al., 2003; Roberts et al., 1992), or chi-square (Ell et al., 2005; Lutgendorf et al., 2000; Manne et al., 2007; McCorkle et al., 2006) for their quantitative data analysis.

2.7 Theory/Framework

Theory and framework were addressed in three of the 20 journal articles. Nail et al., (1986) referred to used coping theories as the framework for their longitudinal study on radiation treatments. McCorkle et al. (2006) used the quality of life framework as their theoretical guide. The concept of quality of life consists of emotional, physical, spiritual, and psychological factors. Manne et al., (2007) used the cognitive-affective-social processing theory and a theoretical perspective on the moderators of change for intervention efficacy.

2.8 Demographics

2.8.1 *Age*

The women's ages in these studies primarily encompassed the middle-aged and Seniors age range. The two youngest groups had a mean age of 40 years old (Carter et al., 2005) and 47.9 years old (Meyerowitz et al., 2000). Two studies had a mean of 50 years of age (Ell et al., 2005; Manne et al., 2007). More than half of the studies had a mean age between 53 and 66 years (Bodurka-Bevers et al., 2000; Bradley et al., 2006; Cain et al., 2006; Carter et al., 2005; Evans et al., 1986; Lutgendorf et al., 2000; Nail et al., 1986; Norton et al., 2005; Parker et al., 2003; Roberts et al., 1992; Wenzel et al.,

2002). Three studies reported ages using medians between 54-59 years (Miller et al., 2002; McCorkle et al., 2006; Zabora et al., 2001). One study reported modal age of 61 to 70 years (Cain et al., 1983). The last study did not report sample age (Cerfolio, 1995).

2.8.2 *Race*

The vast majority of these studies had samples of primarily Caucasian women (Bradley et al., 2006; Bodurka-Bervers et al., 2000; Carter et al., 2005; Kornblith et al., 1995; Manne et al., 2007; McCorkle et al., 2006; Norton et al., 2005; Roberts et al., 1992; Wenzel et al., 2002). Two studies included males and females in their samples, and reported primarily Caucasian subjects as well (Parker et al., 2003; Zabora et al., 2001). One study used an almost equal number of Caucasians (51%) and African-Americans (49%) (Miller et al., 2002). Two studies had primarily Latinos in their samples (Ell et al., 2005; Meyerowitz et al., 2000). The remaining studies did not report the ethnicities of their samples (Cain et al., 1983; Cain et al., 2006; Cerfolio, 1995; Evans et al., 1986; Lutgendorf et al., 2000; Nail et al., 1986;).

2.8.3 *Marital status*

Most of the studies reported more than 50% percent of their samples were either married or living with a significant other (Bodurka-Bervers et al., 2000; Bradley, et al., 2006; Cain et al., 1983; Cain et al., 2006; Carter et al., 2005; Kornblith et al., 1995; Lutgendorf et al., 2000; Manne et al., 2007; McCorkle et al., 2006; Nail et al., 1986; Norton et al., 2005; Parker et al., 2003; Roberts et al., 1992; Zabora et al., 2001).

Three studies reported 41% to 44.9% of their samples were married (Ell et al., 2005; Meyerowitz et al., 2000; Wenzel et al., 2002). Some did not report marital status (Cerfolio, 1995; Evans et al., 1986; Miller et al., 2002).

2.8.4 Education

The studies had a well-educated population with most reporting 33% to 85% of their samples had attended college and beyond (Bodurka-Bevers et al., 2000; Bradley et al., 2006; Carter et al., 2005; Kornblith et al., 1995; Lutgendorf et al., 2000; Manne et al., 2007; Miller et al., 2002; Norton et al., 2005; Parker et al., 2003; Wenzel et al., 2002). One study did not report college information, but 93% of their sample completed high school (McCorkle et al., 2006). Two studies reported their samples had a median educational level of 5.5 years of school (Meyerowitz et al., 2000) and a mean of less than 9 years of school (Ell et al., 2005). The remaining studies did not report education (Cain et al., 1983; Cain et al., 2006; Cerfolio, 1995; Evans et al., 1986; Nail et al., 1986; Roberts et al., 1992; Zabora et al., 2001).

2.9 Empirical Findings

The results of these studies varied with their levels of depression and 6% to 100% of the samples had depression. Four studies reported low rates of depression with 6% (Wenzel et al., 2002), 13% (Cerfolio, 1995), and 17% (Kornblith et al., 1995; Ell et al., 2005) of their sample having depression. Cerfolio's sample also reported a high rate of adjustment disorder and Kornblith et al., (1995) reported anxiety and psychological distress as well. Seven of the studies reported their samples had 21% to 49% depression (Bodurka-Bevers et al., 2000; Bradley et al., 2006; Carter et al., 2005; Evans

et al., 1986; McCorkle et al., 2006; Parker et al., 2003; Zabora et al., 2001). Four other studies reported 63% (Meyerowitz et al., 2000), 96% (Cain et al., 1983) and 100% (Cain et al., 2006) of their samples had depression. Manne et al. (2007) had 100% of their population reporting mild to severe depression symptoms. Mild to moderate anxiety was reported for Cain et al., (1983) and Cain et al., (2006) as well.

Generally, a dissertation includes in the empirical findings chapter a conceptual analysis, but this would be difficult to accomplish due to the studies having a lack of conceptual theories and frameworks. Also, if the following data results section was done conceptually, the impact and details of the empirical findings of these studies would be lost. Thus, the empirical findings for each study will be presented in the following section.

The Cain et al., (2006) longitudinal study on thematic counseling interventions examined three groups: control (n=23), thematic individual counseling (n=17), and thematic group counseling (n=20). All groups reported mild to moderate depression and anxiety at the beginning of the study. Immediately upon completion, all groups had decreased anxiety and depression and 6 months later, the two counseling groups were less depressed and anxious than the control group. The counseling groups also reported better social relationships, fewer sexual difficulties, and engaged in more hobbies and leisure activities.

The Manne et al., (2007) study also examined the effects of longitudinal counseling interventions and had three groups: control (n=111), a coping and communication-enhancing counseling intervention (n=122), and supportive counseling

(n=120). At the beginning of the study, all of their participants had depression symptoms. More depression symptoms were found in younger participants, those with more physical problems, and less emotionally expressive women at the baseline. Depression symptoms decreased over the next nine months for both of the counseling groups indicating the counseling was helpful. Unfortunately, depression symptoms increased for the control group over the nine month period. At the end of the nine months, approximately 65% of the participants were involved in each group.

Kornblith et al., (1995) sample of 151 ovarian cancer survivors reported 17% of their sample had severe depression, 17% had severe depressive symptoms, 22% had severe anxiety, and 33% had high levels of psychological distress. The patients with high distress had the following characteristics: more physical problems, less physical functioning, advanced stage cancer, and inpatient status. They reported more psychological distress and poorer quality of life for patients who died within 120 days of their last follow-up phone call or face-to-face interview.

Evans et al., (1986) reported that in their sample (N=83) of hospitalized women with gynecological cancers, most of whom were newly diagnosed, 23% (n=19) most had major depression and 24 % (n=20) had non-major depression.

Cain et al., (1983) reported 96% of their sample (N=60) of newly diagnosed gynecological cancer patients (diagnosed within one month of the study) had depression: 60% (n=36) with mild depression, 33% (n=20) with moderate depression; and 3% (n=2) with severe depression. Their sample also had mild to moderate anxiety. Women with higher grade tumors (cancer more likely to spread), receiving combination

chemotherapy drugs, or with ovarian cancer had more depression. At the time of their initial diagnosis, the women experienced shock and anxiety.

Ell et al., (2005) reported 17% (n=37) of their gynecological cancer patients (N=222) had depression. Few of their patients were on anti-depressants, seeing a counselor, or in a support group. Younger women were more depressed, as were women with poorer physical and functional status and poorer social and emotional support. Those not depressed were more likely to have been on anti-depressants, anti-anxiety medications, and reported less physical symptoms than the depressed women.

Nail et al., (1986) sample of gynecological oncology radiation subjects (N=30) reported their overall average level of depression was low. Subjects had a variety of physical problems (diarrhea, fatigue, nausea, and anorexia), which peaked during radiation treatments then gradually declined after treatments ended. Subjects were most distressed during their last radiation treatment and distress decreased after completion of radiation therapy. Subjects reported problems in coping with their home environment, hobbies, social activities, and sleeping.

Carter et al., (2005) reported 40% (n=8) of their sample of 20 gynecological oncology survivors, dealing with cancer related infertility issues, were depressed and 35% (n=7) had moderate to severe distress. One year after completing their cancer treatments, half said they were still distressed by the inability to have their own children. This sample also reported sexual problems. The women, “experienced dissatisfaction with their overall sex lives (67%), pain during vaginal penetration (62%), and low levels of sexual desire (56%)” (p. 91). This study identified three themes from

its qualitative question: adjustment and acceptance of the situation, satisfaction at beating the cancer and gratitude for being alive (survival), and negative feelings, such as regret, anger, and grief.

McCorkle et al., (2006) reported 21.3% (n=43) of their 208 cervical cancer survivors were depressed. Depressed subjects had lower physical functioning, more pain, and more post radiation diarrhea than non-depressed subjects. Subjects who had problems at work or problems performing at their job, had their marital status change, or made less than \$ 60,000 a year had more depression.

In the Wenzel et al., (2002) study, 6% of their 49 ovarian cancer survivors reported depression. Their study also reported 25% had physical problems with painful sex. Open-ended questions revealed: 56% of the women would have attended support group meetings had they been offered at the beginning of their treatment; 43% would like to be in counseling at the time they were interviewed; 56% reported their greatest challenge at time of treatment were dealing with the physical side effects; and almost one-third felt that their doctors and nurses being compassionate and sensitive to their needs was helpful. Overall the study reported good quality of life for their subjects. Survivorship distress was examined qualitatively and reported the following distress issues: receiving a cancer diagnosis (85%), having fear of getting a second cancer (36%), having a recurrence (22%), and future testing (30%).

Meyerowitz et al., (2000) study of Latino (mostly immigrants) cervical cancer patients receiving radiation treatment had a sample size of 50 subjects and 63% (n=31) of this sample had depression. This population reported good support and high stress.

Even though they had good support, 44% of them wanted more emotional support. High stress was related to immigration, economic, and transportation problems. This population also reported a wide variety of physical side effects from treatments. More than half (56%) indicated they wanted to speak to a mental health counselor or to other patients (70%). The qualitative section revealed being given emotional support (28%) and maintaining religious faith (14%) were most helpful to them. Most (90%) reported medical staff had been supportive. The majority (84%) was able to properly articulate their diagnosis and felt they would be cured (86%). The group was split when it came to receiving information: 54% believed they received the right amount, 24% received too little, and 22% received too much.

Cerfolio's (1995) study had a sample of 82 gynecological oncology patients referred to the psychiatric liaison that took place during their gynecological oncology treatment for the following reasons: difficulty coping, depression, social issues and "other." Subjects were interviewed and diagnosed using the DSM-III-R criteria. Their sample reported the following diagnosis: 13% major depression, 53% adjustment disorder, 32% adjustment disorder with depressed mood, 12% adjustment disorder with mixed features, and 9% adjustment disorder with anxiety.

Lutgendorf et al., (2000) compared 24 chemotherapy extensively treated and 24 non-chemotherapy early stage gynecological oncology subjects and looked at their emotional well-being. They determined the chemotherapy patients had poorer emotional well-being and more depression than non-chemotherapy subjects. The

chemotherapy subjects also had poorer physical functioning, more fatigue, and less vigor. The study reported coping information as well:

Patients using avoidant coping reported poorer physical and emotional well-being, along with greater anxiety, depression, fatigue, and total mood disturbance. Those using active coping reported better social well-being, better relationships with their doctors and less overall distress (p. 1402).

Both the chemotherapy and non-chemotherapy groups, however, did report good social well-being and reported they were satisfied with their relationships with their doctors.

The chemotherapy patients reported they felt the treatments were worthwhile.

Roberts et al., (1992) sample of 32 gynecological oncology survivors and 100 breast cancer survivors reported that 25 % of the gynecological sample had transitory depression symptoms and slightly more psychological distress than breast cancer survivors. Younger patients also had more distress. The qualitative portion of their study inquired about helpful personnel, helpful resources, what was lacking, and coping. Two-thirds felt their doctors and nurses had been most helpful to them post-surgery. More than 85% were quite satisfied with their interaction with the hospital social worker. However, the remaining subjects would have liked counseling options. When asked about the helpful social work services; one-third mentioned counseling, one-third referred to a psychosocial needs assessment, and the remaining one-third spoke of financial and home care referrals. The most popular coping method was keeping busy and trying to forget about the cancer. Half of the subjects reported lower physical functioning. A large majority (70%) reported no changes in their self-esteem and most of the sample reported good overall quality of life.

Miller et al., (2002) sample of 85 gynecological oncology (ovarian, cervical, and uterine survivors and 42 healthy subjects reported their cancer survivors had slightly better emotional well-being than their healthy subjects. Ovarian cancer patients scored significantly lower on emotional well-being, as compared to cervical and uterine cancer patients. Older cancer survivors had better emotional well-being, but lesser social well-being than the younger survivors. Physical well-being declined the longer the subject had received cancer treatments. Lower overall quality of life was associated with ovarian cancer, radiation, multiple types of treatments, less high school education, and less support at home. This study had almost equal numbers of Caucasians and African Americans in their sample. There were no differences in depression scores for Caucasians or African Americans.

Bodurka-Bevers et al., (2000) sample of 246 ovarian cancer patients reported 21% (n=48) of their sample had depression and 29% had anxiety. “We found that levels of depression and anxiety were higher in women with ovarian cancer than levels found in the general population and that these levels were higher in patients with poor performance status” (p. 306). Poor performance status refers to spending a lot of time in bed resting during the day. Younger patients reported more depression and poorer quality of life than older patients. More physical problems were associated with more depression, more anxiety, and less quality of life emotionally, physically, and functionally. Lower quality of life was also associated with active cancer treatments versus just follow-up appointments.

Parker et al., (2003) surveyed a large sample of cancer patients (N=351) and reported 32% were depressed. Of the 351 subjects 17% had a gynecological oncology diagnosis, 30% had breast cancer, 31% had gastrointestinal cancer and 22% had urologic cancers. Singles had more depression than married subjects. There was less depression for the older and married subjects, as well as those living with a significant other or having a great deal of social support. Older subjects reported less anxiety and good social support. "Patients who were older, married, who had more formation education, or who had less advanced disease reported better overall quality of life in the mental health domain" (p. 189). Overall, the sample reported good quality of life.

Zabora et al., (2001) surveyed a large sample of individuals (N=4496) with 14 different types of cancers: gynecological, breast, lung, colon, head/neck, lymphoma, liver, prostate, brain, melanoma, Hodgkin's, adenocarcinoma, pancreas, and leukemia. Of the overall sample, 3.5% were distressed. Within that sample, 216 (4.8%) of the sample had a gynecological oncology diagnosis. In that gynecological oncology diagnosis group, (n=216), 29.6% reported being distressed. Distress was a combination of depression, anxiety, and hostility scores. More distress was associated with those younger than 30, those older than 80, and having an income from \$80,000-\$89,999 (authors reported this was an unusual finding). Subjects were less distressed if they were married. There were no gender differences in this sample. On an interesting note, pancreatic cancer patients had the most depression and anxiety, Hodgkin's patients had the most hostility, and lung cancer patients reported the most distress (43.4%).

Norton et al., (2005) studied a sample of 143 ovarian cancer patients. The study used Structural Equation Modeling (SEM). The study reported less support was associated with lower self-esteem, which led to more psychological distress. More physical problems were associated with diminished feelings of control and more psychological distress.

Bradley et al., (2006) study involved 152 cervical and endometrial cancer survivors. Of that number 27.6% of cervical cancer survivors and 21.4 % of endometrial survivors had depression. The cervical cancer survivors also had more anxiety, more depression, more anger, and more confusion. Working women reported less depression than homemakers.

2.10 Summary of Risk Factors

The literature review revealed certain risk factors for major depression among cancer patients. Depression was associated with patients who had cancer (Evans et al., 1986), low physical functioning (Bodurka-Bevers et al., 2000; Ell et al., 2005; McCorkle et al., 2006), a great deal of pain (McCorkle et al., 2006), newly diagnosed (Cain et al., 1983), post radiation diarrhea (McCorkle et al., 2006), more physical symptoms (Manne et al., 2007), treatment side effects (Meyerowitz et al., 2000), chemotherapy (Lutgendorf et al., 2000), combination chemotherapy drugs (Cain et al., 1983), ovarian cancer (Bodurka-Bevers et al., 2000; Cain et al., 1983), high grade tumors (Cain et al., 1983); cervical cancer (Bradley et al., 2006), were young (Bodurka-Bevers et al., 2000; Ell et al., 2005; Manne et al., 2007), were single (Bradley et al., 2006; Parker et al., 2003), were unable to have children due to cancer treatments

(Carter et al., 2005), experienced fatigue (Lutgendorf et al., 2000), unemployed (Bradley et al., 2006), immigration and economic problems (Meyerowitz et al., 2000), had changes in marital status (McCorkle et al., 2006), changes in work status (McCorkle et al., 2006), had a family income of less than \$60,000 (McCorkle et al., 2006), had support issues (Ell et al., 2005; Meyerowitz et al., 2000), were less emotionally expressive (Manne et al., 2007), and in those who would like to see a mental health counselor (Meyerowitz et al., 2000).

More psychological distress was noted for patients who are younger than 30 (Miller et al., 2002; Roberts et al., 1992; Zabora et al., 2001), older than 80 (Zabora et al., 2001), have more physical problems (Kornblith et al., 1995; Nail et al., 1986; Norton et al., 2005; Wenzel et al., 2002), less physical functioning (Lutgendorf et al., 2000; McCorkle et al., 2006), have lower support and self-esteem (Norton et al., 2005), poor education (Miller et al., 2002), no help at home (Miller et al., 2002), advanced stage cancer (Kornblith et al., 1995; Lutgendorf et al., 2000), make between \$80,000-\$90,000 annually (Zabora et al., 2001), have sexual problems (Carter et al., 2005; Wenzel et al., 2002), infertility due to cancer treatments (Carter et al., 2005), ending radiation treatments (Nail et al., 1986), or having been hospitalized as inpatients (Cerfolio, 1995; Kornblith et al., 1995).

Poorer quality of life was associated with women who used avoidant coping (Lutgendorf et al., 2000), have ovarian cancer, receive radiation therapy (Miller et al., 2002), receive multiple cancer treatments (Miller et al., 2002), have a low high school education (Miller et al., 2002), are younger (Bodurka-Bervers et al., 2000), and lack of

support at home (Miller et al., 2002). Avoidant coping was also associated with more distress (Lutgendorf et al., 2000). Poorer emotional well-being was associated with chemotherapy (Lutgendorf et al., 2000) and ovarian cancer (Miller et al., 2002). Norton et al., (2005) used structural equation modeling in their study and reported:

As predicted, higher levels of physical impairment were associated with lower perceived control over the illness and in turn, with greater psychological distress. In addition, higher levels of unsupportive behaviors from family and friends were associated with lower self-esteem among patients and, in turn, with greater psychological distress (p. 148).

The literature reports being older, married (Parker et al., 2003; Zabora et al., 2001), having good social support (Parker et al., 2003), being on anti-depressants and/or anti-anxiety medications (Ell et al., 2005), having less pain symptoms (Ell et al., 2005); working (Bradley et al., 2006), and participating in individual or group counseling (Cain et al., 2006; Manne et al., 2007) appear to be protective factors against depression and distress and being older (Miller et al., 2002) is associated with good emotional well-being. Women who have completed radiation therapy (Nail et al., 1986), have good social relationships (Lutgendorf et al., 2000), are survivors (Wenzel et al., 2002), and a good patient/doctor relationship (Lutgendorf et al., 2000) reportedly have better quality of life as well.

2.11 Limitations of Current Analysis

This literature review has many limitations. The articles are difficult to compare as they include studies which vary in gynecological cancer diagnosis, staging, treatments, phase of cancer, and sample sizes. The articles also differ in which mental

health aspect they chose to focus on from depression to distress to emotional well-being to quality of life. The articles varied in whether they were cross-sectional vs. longitudinal and some had unequal comparison groups.

The majority of the studies used older Caucasian females and lacked diversity with the issues of ethnicity and age. Of the 20 studies, 14 reported race composition. Of those 14, 11 used predominately Caucasian samples. Three studies used minorities. Ell et al., (2005) and Meyerowitz et al., (2000) used Latina/Hispanic samples and Miller et al., (2002) used a sample of half Caucasians and half African-Americans (Miller et al., 2002). According to the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) (2009b) study, ovarian cancer race statistics for 2001-2005 found that ovarian cancer did not discriminate according to race. (Ovarian cancer was chosen as the example since the majority of the women in my study had ovarian cancer). According to the SEER study, Caucasian women have the highest rate of ovarian cancer followed by Hispanic, American Indian, African-American, and Asian/Pacific Islander women. The literature does not adequately reflect the significance of the newly diagnosed minorities.

Age was a limitation as most of the studies utilized samples of older women and younger women were under-represented. Only one study utilized a younger population with a mean age of 40 years (Carter et al., 2005). By using a younger sample, they were able to explore infertility distress as an outcome of cancer treatments.

Theory and framework is used to guide research studies, yet 17 of the studies did not utilize a theoretical framework. Only three studies stated their theoretical framework (Nail et al., 1986; Manne et al., 2007; McCorkle et al., 2006).

The generalizability of the studies was limited by their non-probability sampling. All of the studies used convenience sampling. The studies were limited to the United States. It is unclear if international studies would have yielded the same results.

The majority of the studies did employ valid and reliable questionnaires to assess depression and distress with two of the studies utilizing psychiatrists and the DSM criteria (Cerfolio, 1995; Evans et al., 1986). Few had qualitative aspects to their articles, which limited the women's ability to express themselves.

Even though these studies did have limitations, they allow us to see what has been done thus far and where research can be undertaken in the future.

2.12 Conclusions

The studies chosen for this literature review give us some insight into the relationship between depression and gynecological cancer. Even though the National Cancer Institute (2004b) reported that depression affects 15% to 25% of cancer patients, the majority of literature review studies reported depression, depression symptoms, and psychological distress above that level in their samples. Although the results of these studies are not generalizable, the fact that almost all of them had depression in their samples, which was significantly higher than the usual rate of depression in society, allows us to see that this is an area where further research is needed.

CHAPTER 3

THEORETICAL FRAMEWORK

There is one dominant paradigm for depression, the biopsychosocial model. Three theories comprise the model: the biological, psychological, and social/environmental. First the biopsychosocial paradigm will be addressed, and then the theories will be discussed.

3.1 Biopsychosocial Paradigm

A multitude of biological, psychological, and social factors are thought to influence and explain depression. These theories originally were the component behind the psychosocial model but over time it is much more than a model and is now considered a paradigm. For the purpose of this study, the biopsychosocial paradigm will be used.

Engel conceptualized the biopsychosocial model in 1977, in an article that forever changed the face of medicine. Prior to 1977, the only focus for the psychiatric and medical communities with regard to health and disease was the biomedical model. Engel felt that “for many who do have adequate access to health care also complain that physicians are lacking in interest and understanding, are pre-occupied with procedures, and are insensitive to the personal problems of patients and their families” (p. 134). Hence the biopsychosocial model was born. Engle’s felt a person was more than their body and disease and their psychological, social, and behavioral issues should also be

taken into account as well as by the individual's physician. Leigh (1997) stated, "The biopsychosocial approach reminds the clinician to include psychological and social factors when considering the individual patient" (p. 16).

According to the National Institute of Mental Health (2007, p. 3), "Very often, a combination of genetic, psychological, and environmental factors is involved in the onset of a depressive disorder."

In short, a biopsychosocial model and treatment perspective is needed to inform assessment, diagnosis, treatment, and prevention. In the medical profession, the specialties of psychiatry and family medicine have embraced the psychosocial model for about 30 years, although pediatrics and internal medicine have more recently begun to incorporate it into training and clinical practice. Other specialists, particularly the surgical subspecialties, have been much slower to adopt this model (Sperry, 2006, p. 26).

This statement is particularly important to keep in mind for gynecological oncology patients, as the vast majority of them become surgical patients as part of their oncology treatment. The biopsychosocial paradigm will provide a solid and comprehensive theoretical framework for this study of gynecological oncology and depression.

3.1.1 Biological Theories

The biological theories can be broken down into three areas: biochemical, genetic, and chemotherapy theories. A multitude of biochemical/biological theories exist which are believed to explain depression (Kaplan & Sadock, 2005). One of the better-known biological theories is that it is caused by inadequate levels of serotonin in the brain. Individuals are also thought to become depressed due to inadequate levels of norepinephrine and /or dopamine. In addition a lack of cortisol suppression (associated

with pituitary and adrenal receptors), thyroid problems, inadequate growth hormone release when sleeping, sleep abnormalities, abnormal immune regulation, and brain abnormalities, are also thought to play a role in the biochemical aspect of depression.

Genetics (Kaplan, Sadock, & Grebb, 1994) are a factor in depression. Family studies have shown that family members who have had a first-degree relative (examples: mother, father, sister, brother, or child) with depression are 2-10 times more likely to have depression than those individuals who were in the control group. Twin studies indicate the concordance depression rate for identical twins is about 50% and about 10% to 20% for fraternal twins. Thus, if a cancer patient's mother, father, sister or brother, have been depressed in their lifetime, according to this theory, the cancer patient is genetically predisposed to be more susceptible to depression.

Cancer treatments cause major changes in the body and have side effects which mimic depression symptoms. According to the National Cancer Institute (2006), cancer treatments can cause fatigue, changes in appetite, fluctuations in weight, and concentration issues in cancer patients. In addition to biological theories of depression, many other theories exist to explain depression from a psychological viewpoint.

3.1.2 Psychological Theories

The predominant psychological theories of depression include: Beck's cognitive theory, Albert Ellis's Rational Emotion Behavior Therapy theory, Seligman's learned helplessness, and Skinner's operant conditioning theory. One of the most popular theories on depression is the cognitive theory by Aaron T. Beck (1973). According to Beck, depression is caused by the individual's negative or dysfunctional cognitive

beliefs. These distorted thought patterns are based on the individual's prior cognitive experiences. Through a variety of cognitive therapy techniques (Beck, Rush, Shaw, & Emery, 1979), the individual learns to monitor her negative thoughts and replace them with more positive reality-based cognitions. The belief is that once people's cognitions change their affect, the behavior also changes and depression subsides. Cancer patients' negative thoughts may influence their perceptions of the world; and their dysfunctional negative thoughts may contribute to depression.

Rational emotive behavior therapy has its own theory about cognitions and depression. According to Albert Ellis (1962), individuals are reasonable human beings who sometimes have irrational thoughts. These irrational thoughts lead to depression. Once the individual learns to "maximize his rational and minimize his irrational thinking" (p. 36), his depression will subside. One of the elements of this theory has to do with an individual's thinking in "musts" and "shoulds." For instance, a cancer patient might feel she "should" still be there for everyone in her life just as before the cancer diagnosis. She may feel she still has to cook, clean, take care of the children's emotional, physical, and psychological needs as well as her significant other's needs and possibly ailing parents' needs without asking for help with her doctor's visits and recovery, may soon find herself depressed because she "should" still be able to maintain a high-functioning lifestyle while combating cancer.

Another theory used to explain depression is learned helplessness (Seligman, 1975). Seligman's theory of learned helplessness was first conceptualized when he applied electric shock to dogs and studied their behaviors. He placed the dogs in a box

with a divider that was low enough for the dogs to jump over. He then took two groups of dogs: dogs that he shocked and allowed to jump over the divider to safety; and dogs that he shocked and did not allow to escape the painful shocks. The dogs that were allowed to jump to safety did so. The second group of dogs eventually quit trying to escape over the divider once they realized it was futile. They just lay there having learned helplessness and accepted their fate of being shocked. Seligman believes depression is a result of learned helplessness. If an individual believes her actions will make no difference in the outcome of things to come and the end result will be traumatic, this “produces fear for as long as the subject is uncertain of the uncontrollability of the outcome, and then produces depression” (Seligman, 1975, p. 56). Thus, if a cancer patient feels, based on past experiences, that she has no control over her cancer or her condition and feels there is nothing she can do to make the situation better, it is conceivable that she might become depressed.

Skinner’s operant conditioning of depression has to do with reinforcement of the behavior that “operates upon the environment to generate consequences” (Skinner, 1953, p 65). Behavior is controlled by the environment and entails punishers and reinforcers. In regards to depression, Skinner wrote, “Productive patterns of behavior are distorted by strong emotional predispositions, and the operant behavior which is strengthened in emotion may have disastrous consequences” (p 163).

3.1.3 Social and Environmental Theories

In addition to the biological and psychological theories, the social/environmental theories have their own interpretations on the nature of depression. The main theories

are family systems, social learning, and social and environmental stressors.

Bowen (1978) developed the family systems theory. This theory refers to the “relationship system between family members” (p. 104) with regard to the family’s experience with emotional illness. Bowen developed this theory when working with individuals who had schizophrenia and their family members. He believed a family member could become ill in response to the emotional stressors of another person in the family. In this theory, all individuals in the family system are part of an emotional family ego mass. Some individuals are more emotionally enmeshed, have less emotional boundaries, and are sick and weak within in the family unit. Bowen feels, “The stronger side of the family ego plays an important part in creating and maintaining the ‘sickness’ in the weak side” (Bowen, 1978, p. 113). Many times the term “scapegoating” is used to refer to the problem person within the family who is “sick” and becomes the designated scapegoat for all the emotional problems within that family even if the individual is not directly related to the problem or problems. Hence, depression can be created within a family and maintained, as its role is needed in the family. This could possibly relate to a cancer patient who has been seen already as the sick person in the family. A cancer diagnosis could be just what the family needs to keep this person depressed and for them to avoid dealing with the real emotional issues within the family. Bradley, Pitts, Redman, & Calvert (1999) did a study on gynecological oncology patients and stated, “Although the family may provide emotional and tangible support, it may also maintain a woman in a ‘sick role’ discouraging her from resuming healthy activities” (p. 496).

A second theory of depression is the social learning theory. According to Bandura (1977, p. 11-12), “psychological functioning is explained in terms of a continuous reciprocal interaction of personal and environmental determinants. Within this approach, symbolic, vicarious, and self-regulatory processes assume a prominent role.” By watching others demonstrate a desired behavior; individuals form an idea of what they in turn need to do themselves. It is through this vicarious learning that individuals evaluate the consequences of other individuals’ behaviors as part of their own acquisition and self-evaluation process. Individuals who have a positive self concept will pass judgment on themselves in an advantageous manner whereas a negative self concept will elicit a depreciation response in oneself. Bandura wrote about the concept of self-efficacy, which has to do with the successful perception of a goal or event indeed being obtainable by that individual. People who are depressed have a tendency to be harder on themselves especially in the face of failure, have harsh and excessively high standards, belittle themselves when others do something better, and do not view their successes in a favorable light (Bandura, 1995). “Some people suffer depression because they lack the competencies and interpersonal skills to gain satisfaction and minimize adverse experiences in their lives” (Bandura, 1997, p. 343).

Another theory of depression has to do with the social issues and environment. According to Gotlib & Hammen (1992), depressed individuals have difficulties with their social relationships, less social skills, smaller social networks, less social support, and elicit more negative reactions in people than non-depressed individuals. They also report that after a depressed person interacts with a non-depressed person, sometimes

the depressed person becomes more despondent. Research shows there is a link between stressful life events and depression. Depressed individuals have problems at work, with friends, and intimate relationships. Depression negatively influences family relationships between adults, children, and spouse. They state, "Not only are the marriages of depressed individuals characterized by tension and discord, often ending in divorce, but the psychosocial functioning of the children of depressed parents is frequently impaired. Such difficulties undoubtedly contribute to further depression, and contribute to vicious cycles of depression and rejection" (Gotlib & Hammen, 1992, p. 191). That being said, not only will the cancer diagnosis affect the patient, but her depression can have a negative effect on her family as well. The National Cancer Institute (2004b) also reports financial problems, legal issues, life plans being put on hold, body changes, and impacted lifestyles are just a few of the social problems a cancer patient and her family may face.

According to Mirowsky & Ross (1989), there are certain characteristics that influence one's level of distress: socioeconomic status, marriage, raising children, gender, many instances of unexpected change in one's life, and age. Socioeconomic status is described as one's occupation, level of education, and salary. Research has shown individuals with better jobs, more education, and more money have less distress. Marriage has shown to be beneficial in terms of distress as it appears to protect people and gives a built-in support as opposed to being single. Individuals who are raising children have more distress than those without children. Gender is a well-known characteristic of distress as "women are more distressed than men" (p. 75). Having

many unplanned changes in ones' life is also considered to be more distressing than having life being planned and stagnant. In addition, "middle-aged people are the least depressed, but older people are least anxious" (p. 75).

Additional qualities (Mirowsky & Ross, 1989) are thought to explain why some people become distressed while others do not. The first one is a sense of control over the content in one's life. "Resources that give individuals real control over their own lives, such as education or income, increase the level of perceived control that minimizes depression (p. 252). Positive attributes such as support from others and having people to trust play a role in less distress as well. Individuals who finding meaning in their lives and make commitments to the actions in their lives also have less distress. Flexibility in one's life, finding normality, and feeling situations are equitable are also positive protective characteristics of people who do not become distressed.

CHAPTER 4

METHODS

As previously stated this gynecological oncology population has received limited attention with regards to research from the medical and academic communities. In order to give the participants a voice and to capture the depth of their experiences a qualitative design was chosen for this study.

4.1 Rationale for Qualitative Design

“Qualitative methods are often employed in unstudied or understudied areas” (National Institute of Health, 1999, p. 4). Gynecological oncology is indeed an understudied area so this method of design is applicable for this study. Qualitative research is essential for this study to explore women’s experiences, as quantitative research alone is unable to capture the breadth and depth of those experiences. Qualitative research will allow the researcher to capture the participants’ point of view and secure rich descriptions (Denzin & Lincoln, 2000) of their experiences. According to Prevention Communication Research Database (2007), qualitative research allows one to explore a topic and gain insight into how people think and feel about the topic being explored. The qualitative research method attempts to “clearly describe gaps in current knowledge” (National Institute of Health, 1999, p. 3) and this design and study will ultimately expand the knowledge in this area.

Holman (1993) feels that qualitative research is necessary for chronic health related issues. He reports that qualitative research is lacking in the medical and academic communities. He states:

If criticism is warranted for the absence of qualitative inquiry in the mainstreams of contemporary medical research, it should be directed primarily at ourselves and at our academic institutions. The almost sole recognition given to quantitative methods has trained students inadequately, established flawed standards of practice and research, and delayed the development of essential medical knowledge. But recrimination concerning the past has limited value. The task is to determine where we go from here given the complex health problems which must be addressed. Good clinical thought requires recognition of the co-existence of generality and individuality. Similarly, good medical research requires recognizing the complementarity and interpenetration of quantitative and qualitative methods of inquiry. When qualitative methods are clearly established in our research repertoire, the advance of medical knowledge will be greatly accelerated (p. 36).

According to Casebeer & Verhoef (1997), “Qualitative research is usually seen as a method seeking better understanding of some particular, natural (uncontrolled) phenomenon” (p. 3). This research study will explore the phenomenology of women with gynecological oncology and their lived emotional experiences with and without depression, using qualitative methods.

According to Pitney and Parker (2002), “Phenomenology focuses on the meaning of the lived experience” (p. S-169). Phenomenology provides insight into how people make sense of their lived experiences and their perceptions of the world they live in (UK Medicines Information, 2007).

This study will utilize a semi-structured interview to obtain the data which will then be analyzed for themes. Van Manen (1990) feels interviewing subjects serves a

specific purpose as, “it may be used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon” (p. 66).

4.2 Instruments

Data collection for this study was done one-to-one and face-to-face as part of the semi-structured interview. I shared with the participants that I was interested in learning about their lives, their emotional experiences, and their insights into their oncology diagnosis. I wanted them to be able to share the good and the bad aspects of their gynecological diagnosis to give me a complete picture as that would shed light on their emotional coping. I needed to know about all aspects of their cancer experience, emotions, and coping, as some may or may not have had a depression experience.

Data collection questionnaires were used during the interview process, which I created for this study. They included the following questionnaires: demographics, gynecological oncology diagnosis, and mental health history.

The demographics questionnaire (see Appendix C) addressed age, ethnicity, marital status, source of income, annual income, number of children, children’s ages if applicable, and children’s area of residence, if applicable. The gynecological oncology diagnosis questionnaire (see Appendix D) contained questions about the type of cancer, stage, age at diagnosis, treatments, and additional cancer diagnosis. The mental health history questionnaire (see Appendix E) included questions about depression, anxiety, generalized anxiety disorder, bipolar disorder, and schizophrenia diagnoses.

The semi-structured interview questions were created based on the literature review as it revealed certain aspects of a person's life could affect their emotional well-being, psychological distress, or depression and these factors were included in the interview questions. Some of these aspects included physical problems, side effects of the different treatments, support, emotional reactions, relationships, economics, work, age, fertility, different cancer types, education, coping, and being hospitalized, to name a few.

After the data collection questionnaires were administered verbally, the semi-structured interview questions were then asked one by one and these were divided into three categories: pre-diagnoses, diagnosis, and post-diagnosis (see Appendix F). The post-diagnosis section allowed for the exploration of depression or depression symptoms in detail if the participant endorsed these items retrospectively. These three established categories allowed me to see what the participants' lives looked like before and after their oncology diagnosis, how the journey affected their emotional state, if at all, and how they viewed their lives during different time periods. By structuring the questions in this manner, it provided a timeline and allowed me to follow the participants' journey in a chronological manner. Since the interview was semi-structured, it allowed me the latitude to ask additional questions during the interview for clarification or exploration.

4.3 Participants

Initially the goal for this study was the recruitment of 7 to 10 women between the ages of 18 and 42 years with a gynecological oncology diagnosis (in their lifetime),

who had received chemotherapy, and lived in Tarrant or Dallas counties.

Gynecological oncology diagnoses included: ovarian, cervical, endometrial, vaginal, trophoblastic, and vulvar cancers. Participants were included with any stage of gynecological cancer. The study was open to women of all races and ethnicities. Due to my inability to speak a foreign language, I chose to include only women who spoke English fluently. I initially chose to use Tarrant and Dallas counties for convenience for myself and the participants as the interviews were going to be face-to-face. Later in the study, I sought and received IRB approval to expand my geographical area to further assist with recruitment efforts.

With regard to my participants, a critical change took place with their age criteria during the dissertation process. Based on the literature review, it was decided by my Committee and myself that since younger women had more distress and were under-represented, I should focus my attention on women of child bearing age between 18 and 42 years of age. I spent months attempting to recruit these younger participants, but had very limited success. The first person to volunteer for the study was unfortunately over the age limit criteria. The second person to inquire met the age criteria and became a participant in this study. For more than two months, I attempted to recruit women of child bearing age, but to no avail. I subsequently went back to my Committee and explained my dilemma. I received their approval and the IRB's approval, on December 14, 2008, to eliminate my age criteria, thus allowing women older than 42 years of age into the study. Subsequently, I was able to interview nine

more women for the study. Eight were older than 42 years of age and one was 28 years old.

4.4 Sampling Methods

Non-probability convenience sampling and snowball sampling was used to obtain subjects. Once IRB approval had been obtained, recruiting fliers were handed out and/or posted at a variety of venues that women with gynecological oncology might frequent. Recruitment fliers were distributed at the following locations: Dallas Ovarian Cancer Support Group-Baylor, the Fort Worth Meet and Eat Support Group, Gilda's Club of North Texas, Arlington Cancer Center, multiple Texas Oncology locations, and a local women's church meeting. Recruitment efforts began after IRB approval was given in late September 2007 and ended six months later, in mid-March 2008, when the goal of 10 participants' interviews was reached.

Whenever a potential participant contacted me, I described the study, which included the purpose of the study, the criteria, what to expect, the expected length of time to complete the interview, IRB approval received from the University, and that the interview was voluntary, confidential, one on one, and taped. If a subject gave her consent, we then set up an interview date at a neutral location.

The face-to-face interviews took place over the course of many months in a wide variety of North Texas cities, including Dallas, McKinney, Desoto, Fort Worth, and Arlington. The interviews took place at UTA's School of Social Work, Gilda's Club of North Texas (a cancer support center), hometown libraries, and an office building. Private offices, study rooms, and conference rooms were utilized when

available. Two of the interviews took place at Gilda's Club of North Texas in Dallas. Two took place at UTA's School of Social Work in Arlington. One took place in an office building in downtown Fort Worth. Five of the interviews took place at the participants' hometown libraries in McKinney, Desoto, Dallas, Fort Worth, and Arlington. I told them I was happy to drive to their hometowns to interview them so they would not be inconvenienced. Three of the interviews took place during the week and the other seven were on a weekend.

4.5 Informed Consent

Before obtaining Institutional Review Board (IRB) approval for this study, I presented my dissertation proposal to the Dissertation Committee. Upon receiving my Committee's approval, I submitted my dissertation proposal to the IRB at the University of Texas at Arlington. I received IRB approval on September 26, 2007.

4.6 Data Collection Procedures

Upon meeting the subject face-to-face, but prior to the semi-structured interview, consent forms were explained, the study was explained again, and a written informed consent form was signed. Once again, it was reiterated to the participants that their participation was voluntary and they could withdraw at any time. Due to the personal, emotional nature of the interview questions, each individual was offered a written list of counseling resources at the end of the interview.

Participants were advised their information was to be kept confidential and they would each be assigned a number to de-identify them. Participants were informed the data collection tools and the logbook key would be kept separate and locked up at the

School of Social Work. The items will be kept there for the next three to five years. At the completion of the study, the logbook with the participant's names in it would be shredded.

Participants were first questioned about their demographics, their gynecological diagnosis and mental health history, before the semi-structured interview began. A tape recorder was used to record their answers, and for transcribing the interview later. I also took notes during interviews. A few individuals cried at various times during the interview, either when remembering their ordeal or when remembering their friends who had died of cancer. In these few instances, sometimes a quick break was needed for the participant. Upon completion of the interviews, the participants were thanked for their time and offered a list of counseling resources.

4.7 Data Analysis

The only source of data for this study came from the semi-structured interview with the participants. The 21 hours of audio-tapes were the center of this data analysis. The audio-tapes were transcribed verbatim. In order to get the essence of the interview, I read through the text once without any type of analysis. Then I read through the text a second time using Creswell's (2007) data analysis approach. With the second read-through, I made notes in the margins about their content of the text. I took note of positive and negative items and reoccurring items. I then looked for meaningful units and significant statements in the text, which I later began grouping into themes. Once themes were identified, I went back to the text to identify quotes that would be used to support the themes to give them a rich description. By the time the text analysis was

complete, I had read each text numerous times with a critical eye to determine if I had captured the essence of the women's experiences.

Later, upon the completion of the data analysis, I compiled and summarized the data collection questionnaires. These questionnaires included: demographics, gynecological oncology diagnosis, and mental health history, which provided further descriptions of the participants. The main gynecological oncology diagnosis demographics were then compiled into table format for quick referencing (see Appendix B or Table 5.3).

4.8 Validity

According to Whittemore, Chase, and Mandle (2001) there are many techniques that can be utilized to demonstrate validity in a qualitative study. They suggest techniques to address validity in the areas of design consideration, generating data, analytic functions, and presentation.

In design consideration, techniques such as sampling decisions, giving the participants' a voice, and allowing an oppressed group to express themselves are important factors for validity Whittemore et al., (2001). For this study, a responsible sampling choice was designed to use 10 participants to capture the essence of the experiences. A sample size up to 10 is recommended for a phenomenology study (Dukes, 1984).

In designing this study, it was necessary to give the participants a voice because such stories have not been actively sought out by the medical and educational communities, and the rich detail of the descriptions of their personal experiences are an

important part of gynecological oncology research.

With regards to oppression, according to the FreeDictionary.com, one definition of oppressed means to “weigh heavily on.” When many of these women were diagnosed and discovered there were few books on gynecological oncology in libraries, but numerous books on breast cancer, they very well might have felt heavily weighed upon. One of the participants pointed out this discrepancy during our interview. She expressed surprise and disappointment when she saw so many books on breast cancer and the meager section on ovarian cancer. Keeping that in mind, this study offers these research-oppressed women a voice to express themselves and to share their experiences.

Data generating validity techniques deal with issues such as demonstration of prolonged engagement, verbatim transcriptions, and saturation of themes (Whittemore et al., 2001). Lincoln and Guba (1985, p. 301) define prolonged engagement as “the investment of sufficient time to achieve certain purposes; learning the ‘culture’ ...” As a gynecological oncology social worker, I was immersed in that culture for many years, thus peaking and sustaining my interest in working with this population. Once the interviews were completed, the audio tapes were transcribed verbatim and the saturation was utilized for theme identification.

During the analysis phase, I used validity techniques such as memoing and reflexive journaling. Memoing and note taking were used during the data analysis process, as well as during the interviewing process. In addition, I engaged in reflexive journaling, which took an interesting turn in April when I branched out and began to write poetry about cancer during the data analysis phase.

The last type of presentation validity technique is in the actual presentation of the data itself. This includes “providing thick descriptions” and “providing evidence that supports interpretations” (Whittemore, Chase, & Mandle, 2001, p. 533). Rich descriptions of the themes coupled with quotes from the participants will achieve this type of validity in its written presentation.

4.9 Limitations of Current Study

Like many other studies, this study too had certain limitations. First, this particular sample of 10 women who volunteered for the study were highly motivated and all belonged to support groups. This study did not include non-volunteers, non-support group members, or inactive participants. This study did not use triangulation, medical records, or diagnosing tools. It was a retrospective study and did not involve diagnosing mental health issues. Another limitation was the period of data collection as there was only one interview and no follow up. Also, there was no control group in this study. It is unknown what the results might have been had these other groups been included in the study. Perhaps other groups of women would have expressed different ways of coping with their experiences.

4.10 Summary

Even though this study has limitations, it will give women with gynecological oncology a voice about their experiences. The hope of this study is to shed some light on the emotional and depression aspect with this medical diagnosis. It is anticipated that the information obtained from this study will add to the existing literature and may

be used to help women with gynecological cancers, in the medical, academic, and other important venues.

CHAPTER 5

RESULTS

This following section will address the results of the data collection and analysis. First the results of the questionnaires will be discussed then some of the answers to the interview questions will be detailed then identifiable themes will be addressed.

5.1 Participants

The 10 participants in this study ranged in age from 28 to 67 years old with a mean age of 49.5 years. The youngest two were 28 and 32 years of age. The remaining eight participants ranged in age from 47 to 67 years old. The ethnic composition consisted of seven participants who were Caucasian, one was Caucasian/American Indian, one was Asian, and one was Hispanic. This group was well-educated. Two had high school degrees, five had Bachelor's degrees with one having taken graduate classes, two had Masters, and one participant had a Doctorate.

In terms of religious orientation, nine of the participants identified themselves with Christianity and one with Buddhism. Two of the participants were single, one was separated, one was widowed, one was divorced, and five were either married or living with a significant other. More than half of the women (n=7) lived with someone: either with their husbands, boyfriend, children, and/or grandchildren. The remaining three women lived alone. Seven of the women had children. Of these seven, all had at least

one adult child residing within the state of Texas. One participant reported she is the primary caregiver for her granddaughter and a second participant reported she is the financial caregiver to her parents.

Five of the women were employed. Those not currently employed received their income from one or more of the following sources: social security/social security disability, commercial disability, pensions, savings, or spouse's income. All ten of the women had medical insurance. Household incomes ranged from \$15,000 to \$175,000 a year. The women lived in a variety of counties in North Texas with four residing in Tarrant, three in Dallas, one in Parker, one in Collin, and one in Ellis.

5.2 Gynecological Oncology Diagnosis

The results of the gynecological oncology questionnaire will now be discussed. Six of the participants had been diagnosed with ovarian cancer, one had been diagnosed with ovarian and pancreatic cancer, one with cervical cancer, one with endometrial cancer, and the last one had been diagnosed early in life with cervical cancer, then at age 49 with cervical and vaginal cancer and later cancer was found in her lung. All 10 participants received chemotherapy. Nine of the 10 women received surgery (one or more surgeries) as well. The three participants with cervical, vaginal, or uterine cancer also received radiation therapy. None of the participants with ovarian cancer received radiation therapy as this is not the protocol for treating this type of cancer.

Table 5.3, the Demographics and Gynecological Oncology Table represents the participants' gynecological oncology information:

Table 5.3 Demographics and Gynecological Oncology Table

| Age | Race | Type of Cancer | Age at Diagnosis | Staged | Surg | Chemo | Rad |
|-----|-----------------------------|---|---|--|------|-------|-----|
| 28 | Asian | Cervical | 27 | Stage 3B (Initially staged as 2A) | Yes | Yes | Yes |
| 32 | Caucasian | Endometrial | 31 | Stage 3A | Yes | Yes | Yes |
| 47 | Caucasian | Ovarian & Pancreatic | 46 | Stage 1C = Ovarian Pancreatic = Not staged (early stage) | Yes | Yes | No |
| 49 | Caucasian | Ovarian | 46 | Stage 4 | Yes | Yes | No |
| 49 | Caucasian | Ovarian | 47 | Stage 2C | Yes | Yes | No |
| 50 | Hispanic | Ovarian | 49 | Stage 3C | Yes | Yes | No |
| 52 | Caucasian & American Indian | 1. Cervical 2. Vaginal & Cervical 3. Lung | 24 = Cervical 49 = Vaginal & Cervical 51 = Lung | Cervical = Not staged (early stage) Vaginal/Cervical = Believes it was Stage 3 Lung cancer = Unsure if it is a new cancer or if the vaginal and cervical cancer spread | Yes | Yes | Yes |
| 58 | Caucasian | Ovarian | 51 | Stage 3C | Yes | Yes | No |
| 63 | Caucasian | Ovarian | 57 | Stage 3C | Yes | Yes | No |
| 67 | Caucasian | Ovarian | 62 | Not Staged (Cancer was considered late stage) | No | Yes | No |

At the time of the interview three of the participants with an ovarian cancer diagnosis were in chemotherapy due to having a recurrence. A fourth participant with ovarian cancer was going to start chemo again within days of the interview. The three remaining participants with an ovarian cancer diagnosis had not had a recurrence, but one was scheduled for some testing as her abdomen was getting bigger and she was concerned that perhaps the cancer had returned. The two participants diagnosed with endometrial cancer and cervical cancer were not in chemotherapy at the time of the interview, nor had they had a recurrence. The remaining participant had been diagnosed with cancer three times in her life. She first had surgery for cervical cancer at age 24, then at age 49 when she was diagnosed with cervical and vaginal cancer and treated with surgery, chemo and radiation, and at age 51 when diagnosed with cancer in her lung. It was unknown if the cancer in her lung was a new primary cancer (lung cancer) or if it was cervical cancer that metastasized in her lung. Due to the different time periods involved in this participant's cancer diagnosis, the participant chose to focus the interview questions on the cancer diagnosis at age 49 and beyond, rather than at age 24. She received surgery only at age 24 and reported it was not a serious case of cervical cancer, but the cancer diagnosis she received at age 49 and later was very serious, and very extensive treatments were needed. In all, four of the participants currently were being treated for cancer and of the remaining six participants, five had completed their cancer treatments within the past year or less, and one had completed her treatments within the past 2 years. The participants' cancers ranged from stage 1 to stage 4, with the majority of the participants having stage 3 cancers.

5.3 Mental Health History

Each participant was asked questions about their mental health history. None of the 10 participants had ever been diagnosed with bipolar disorder, schizophrenia, or generalized anxiety disorder.

When asked if they had ever been diagnosed with major depression two participants gave answers other than no. Prior to being diagnosed with cancer, one participant had been diagnosed with depression 12 years earlier due to a divorce and had received help for it (counseling and psychotropic medication). The second participant saw many counselors after being diagnosed with cancer and one of them told her she was depressed, but she did not know if she was actually given a diagnosis. None of the counselors ever referred her for medication management. When asked if the participants had ever been diagnosed with anxiety disorder, one of the 10 women reported yes. She said she had anxiety and depression after her cancer diagnosis. Later in the interview, she reported in her past she had had a great deal of distress associated with a previous relationship.

Much later in the interview, a few of the women shared more about their past. One shared that she had been in therapy for five years prior to having cancer, due to her dysfunctional childhood, and was in a good place emotionally when she was diagnosed with ovarian cancer. Another remembered that after her cancer diagnosis she had a bowel obstruction and was critically ill in the hospital for 17 days. On her second day of her hospital stay her parent died. She said she was depressed, and a psychologist was sent to see her in her room. From my experience, this is quite a common occurrence in

a hospital setting, to send a psychologist in to talk to a hospitalized critically ill bereaved patient.

Two participants acknowledged previous drug/alcohol histories. One participant reported long-term alcohol abuse and drug use/dependence prior to her cancer diagnosis. A second participant acknowledged she abused alcohol many years earlier in her life (prior to her diagnosis). Alcohol and drug use were no longer an issue for either participant.

Domestic violence was not a question in the interview, but three participants reported a history of domestic violence. Two were raped as children and both feel their cancer diagnoses are perhaps linked to this trauma. A third participant had been in a long-term domestic violence relationship with her spouse many years ago.

5.4 Interview Questions

Next some of the results of the interview questions will be discussed. Even though the following information did not warrant a theme, it does have value in this study and should not be dismissed.

5.4.1 Gynecological Oncology Information

The seven participants diagnosed with ovarian cancer had a variety of symptoms prior to diagnosis. When she laid on one side, one participant reported low-level discomfort and mood swings, which made her cry at the drop of a hat. A second participant had heavy bleeding for several days, a fibroid tumor, and a cyst on her ovaries. A third participant had overwhelming fatigue, abdominal pain, pressure with intercourse, and a swollen belly which made her unable to zip her pants. The fourth

participant had total exhaustion, a rash on a large area of her body, shortness of breath while exercising, painful joints, weight loss, diarrhea, bloating, painful intercourse, and a big stomach. The fifth participant felt fatigue, had weight gain, and found it difficult to zip up her pants. The sixth participant had weight gain, bloating, severe fatigue which almost put her job in jeopardy, constipation, and she reported she looked pregnant. The seventh participant had a bellyache and abdominal pain. Of the remaining three participants: the participant diagnosed with vaginal and cervical cancer discovered her tumor while bathing, the participant with cervical cancer felt a sporadic pelvic “pulling pain” that got more and more frequent, and the participant with uterine cancer had heaving bleeding and irregular periods.

Half of the participants were misdiagnosed. One ovarian cancer participant was told she had a bladder infection and was given an antibiotic. A second ovarian cancer participant was told she was doing too much (she was in her 40’s) and to slow down, then misdiagnosed with irritable bowel syndrome, herpes, and colon cancer. A third ovarian cancer participant was misdiagnosed with irritable bowel syndrome, menopause, and a thyroid problem. A fourth ovarian cancer participant was misdiagnosed with lymphoma and breast cancer. A fifth participant with cervical cancer was told it was just stress and to take pain pills, exercise, and learn how to relax.

The two younger participants differed from the older participants in that neither one had children and now due to their cancer treatments both had infertility issues. Eight of the remaining participants were past child bearing age. Of those eight, seven

had children. Both of the younger participants were within child bearing age and both reported infertility was an emotional loss for them.

Five of the 10 participants reported sexual difficulties due to their cancer treatments. Of these five women, four were in relationships and one was single. Of the four women in relationships, one shared that since her husband's libido had decreased sexual difficulties were no longer a problem.

5.4.2 Bothered Them / Sense of Loss

When asked the questions about what bothered them the most about having cancer or what was their greatest sense of loss, they reported the following answers: One of the younger women said infertility; the second younger woman said infertility and loss of sex drive; the third woman said the side effects of the chemotherapy, having a port (a port is attached to a catheter to administer chemotherapy into the body), the loneliness, and how people treat you when you have cancer; the fourth woman said it was the pain; the fifth woman said it was the side effects of the chemotherapy, not being able to take care of her large garden, and hating her port "with a passion"; the sixth woman said it was loss of her muscles, not feeling coordinated or strong anymore, loss of normal sexual and physical function, and getting a lung biopsy; the seventh woman said it was when the doctor went in to fix her bowel obstruction and did not take any of the cancer out during that surgery and her hair loss; the eighth woman said it was her hair loss, loss of femininity, loss of libido, sexuality, and feeling like a eunuch; the ninth woman said it was the effects of the chemotherapy; and the tenth woman said it was her hair loss, her port, and a sense of having no control. While hair loss was a traumatic

event for some of the participants, a few other participants did not mind their hair loss, and one in particular reported she loved being bald.

5.4.3 What Can Be Done Better

Participants gave their feedback and suggestions on what they did not like and how things could be done better in a medical setting to help other women in the future: Men and women should be separated for chemotherapy; there should be curtains for privacy; there should be a chemo “floater” volunteer who speaks to the women during chemotherapy treatments; there should be a cancer survivor to speak to newly diagnosed patients in their hospital room; medical staff should be more concerned about germs and hand washing; nurses should speak English fluently; all cancer patients should have a cancer advocate; hospitals should have their own outpatient cancer therapists and nutritionists on staff so a patient with cancer does not have to find such specialists on their own; doctors should refrain from having a serious conversation with a patient while he is examining her under a sheet; doctors should provide written resources to every new cancer patient including information on Gilda’s Club; it would be nice if a nurse actually answered the phone at the oncology office rather than patients having to leave a message; women should not be placed in the same exam room where they were diagnosed with their cancer; there should be written resources to read while in the exam room; there should be a diagram of the woman’s body in the exam room so the doctor can show the patient exactly where the cancer is in relationship to her organs; wait times at the doctor’s offices should be shorten; if the doctor was running late, the staff should contact the patient and advise her to arrive a bit later; doctors should

provide post-treatment advice such as talking about how lymphedema is an issue with cancer patients while flying in an airplane and how to address it; doctors should give patients a list of what symptoms to be aware of for a recurrence; hospital bedside staff should be more compassionate; medical staff should not assume because a patient herself is a nurse that she does not need the same information as everyone else; the importance of support groups needs to be emphasized; doctors should explain things in very simple terms while a newly diagnosed person becomes familiar with cancer terminology; doctors with long-standing relationships with patients should call those patients after they receive a cancer diagnosis; and women should have somebody with them when receiving the cancer diagnosis.

5.4.4 Cancer Resources /Information

Seven of the participants reported they received written resources and/or booklets after being diagnosed. One reported her doctor's office gave her information on uterine cancer when she actually had ovarian cancer. Three participants did not receive any resources or booklets about cancer and reported they would have liked to have received the information.

5.5 Themes

The following 11 themes emerged as a result of the data analysis: *Wide Range of Emotions at Diagnosis, Advocacy, Spirituality, Complex Support Systems, Support Groups, Chemotherapy Side Effects, Longevity, Personal Growth, Bonded with Doctors, Medications, and Counseling.*

Many times these themes appear to overlap. For instance, one participant said, “God and [her physician’s name] cured me.” This type of statement could have been included in either the *Spirituality* theme or the *Bonded with Doctors* theme. Each theme will be discussed and the participant’s quotes will be used to support the theme. For each participant to have a voice, each participant will be quoted twice or more within this dissertation. Within each individual theme, a participant will be quoted only once. There are two exceptions to this, however, as I will quote one person twice in the *Longevity* theme. Then later in the *Bonded with Doctors* theme I will also quote one participant twice, once for a positive quote and once for one negative quote. I am choosing not to put any identifiable demographics next to the quotes to give the participants some privacy. In addition, if during the quote they mentioned their own name, friend’s name, bosses name, or doctor’s names, I took these identifiers out as well.

Next the themes will be discussed in detail.

5.5.1 Wide Range of Emotions at Diagnosis

As one would expect, being handed a cancer diagnosis is a devastating, life-altering experience. Participants either received their diagnosis over the phone or in person. Neither group was dissatisfied or would have rather had a different mode of delivery (in person versus phone). Two participants were not pleased with their physician’s manner of delivery: one doctor was very negative and the other lacked compassion. The participants had a wide range of emotional responses when they received their diagnosis: shock, being stunned, crying, disbelief, frightened, panicked,

overwhelmed, terrified, scared, devastated, depressed, stressed out, grief, anger, nervousness, feeling vulnerable and very clingy, feeling an adrenaline rush, feeling of being handed a death sentence, feeling of being “in the twilight zone,” reflective, fleeting thoughts of boycotting the chemotherapy and allowing death to come, uncertainty, feeling dead emotionally, feeling of no control, weepy, not knowing what to do, having nightmares, wanting to be numb, using avoidance, feeling disappointed, loneliness, regret, having an restive mind that would not shut off, feeling the need to reach out to her support network, feeling guilty about abusing one’s body and /or living an unhealthy lifestyle, and feeling overwhelmed and pressured because of the diverse treatment options, and expected to be an expert and make a good treatment decision while trying to deal with the learning curve. In the following quote, one participant describes her reaction to being told she had cancer over the phone at home with her husband on the other house phone with her:

I mean, just immediately, you get this adrenaline rush from the top of your head all the way down to your body and just complete shock. I mean, the first thing actually I wanted to do was to lash out at my husband, but I just walked away from the room because I thought, you know, it’s not his fault. Because he said something, I don’t remember what he said. But I just needed, um, just, you know, 30 minutes or something just to try to breathe by myself. It’s just really...it’s something that is hard to explain.

One of the younger participants describes her experience with her doctor:

And it was really just kind of surreal, I guess. Like, I don’t remember driving home after it. I remember sitting in the office, and they were already playing Christmas music on the radio and somebody turned the radio on in that exam room. There was a little radio off on the side. It was happy Christmas music. I’m just like not expecting anything. Then she told me, and I didn’t know what to think or what to say. And I remember she said why don’t you call your mom

and talk to her. If she needs to come and get you or if she needs to come and talk to me or whatever. So she left and I called my mom. And I don't remember what I said. But I just decided to go on and drive myself home. Sorry, I haven't really thought about this. (Crying) She just said, she said she was sorry, and that she had no idea. She didn't expect it at all. And she had been on the phone all morning with the lab before I came in to make sure they didn't make a mistake with the results. She told me that it was grade 3. I didn't know at the time the difference grade and stage. So when I got home and started thinking about it that kind of freaked me out.

A second participant describes her emotional state at diagnosis:

Dead. Like so over the top emotionally. Like no other emotion could come in. Devastated, also reflective, and I think you really look back on everything, you know what is it for? What will happen now as far as me and my kids, and, what was it all about, why did I focus on those things and not on other things. And yeah, I think it's a whirlwind. It's hard to keep up with all the emotions, and it's nonstop, or with me it was nonstop, and for months and months, I did a lot of thinking. I got tapes that were kind of meditative, but I really liked just soft music, and they're called something. They actually have a name to them. Somebody sent them to me. Oh, I can't remember, but there's different ones, like *Successful Surgery*, *Getting Through Chemo*—they're very nice. They got me to at least relax for a little bit, because most of the time I was pretty highly stressed, emotionally.

Another participant describes her emotions and thoughts at diagnosis:

Uncertainty. Where was I going to live, what was going to happen about my job? Well, the first question is am I going to lose my hair? And she said, 'Yes, you are.' And I was devastated by that. I did not want to lose my hair. So, you know, I just think I was just like totally freaked about everything. I was just scared about everything and the uncertainty of everything.

One participant described her reaction when she read about her condition:

The doctors come in and say this and that, and I don't know what that means, you know. Some of my co-workers had like breast cancer, and so they knew. They're the ones who brought me the books, and I would read it and it just terrified me.

Another participant who received her news from an insensitive, negative doctor describes her reactions and thoughts:

So my sister-in law says to me, she had open heart surgery earlier in the year, so she was just, she had just gotten back on her feet when I did my thing. She said, 'You can beat this (laughs). You're going to fight. You've done it before.' And you know, that stuck with me and she was right. She said, 'That doctor made you mad,' (laughs), and she was right. And I, I sort of became determined I was going to show him. So I've had, you know, I've had a whole range of emotions from feeling like I was dead, to I'm not going to let this get me, to, you know, to we're just going to live each day as it comes and enjoy what we can.

5.5.2 Advocacy

The second theme is *Advocacy*. According to Webster's New Collegiate Dictionary (1980), the word advocate is defined as "one that pleads the cause of another," and "one that defends or maintains a cause or proposal." It defines advocacy as "the act or process of advocating; support." The participants in this study do that and more, as they are very active in the community in participating in education, creating awareness, supporting each other, and fundraising.

The following are a list of the participants' various advocacy ventures and projects. They start support groups, teach medical students how to positively interact with oncology patients, lobby on Capitol Hill, write articles for hospital newspapers and magazines, participate in Ph.D. studies, attend events like Cancer Forums and Lance Armstrong Summit, become "Chemo Angels," attend Health Fairs, work on fundraisers, distribute cancer literature, volunteer for the National Cancer Coalition, make fundraising videos at Gilda's Club of North Texas, participate in peer counseling,

distribute support group literature, contact newly diagnosed patients to offer support and guidance, actively volunteer with the American Cancer Society to distribute educational materials, give other cancer patients rides to chemotherapy, make supportive cancer videos to help hospitalized cancer patients, give presentations in the community to various groups, aspire to volunteer at Cancer Camp, create CBT therapy programs specifically for cancer patients, and some of the participants even wrote an ovarian cancer survivors' book, *TORCH: Tales of Remarkable Courage and Hope*, which was published and is for sale on Amazon.com. In keeping with the advocacy theme, three participants took the opportunity to educate me on their cancer diagnosis and provided me with well written literature. I received the book *TORCH: Tales of Remarkable Courage and Hope* from one of the participants. A fourth participant wanted to give me the book as well, but I had already received a copy.

The women cited various reasons as to why they were involved in advocacy work. The main reason was to help other women now and in the future. Helping others not only makes them feel good, but they get to share their vast knowledge with others and this gives them a sense of peace and purpose. It also gives them a sense of hope, which they wish to instill in other women. In raising awareness with the public, they feel this will in turn help others understand cancer is not a death sentence, and there is a lot of living to do, a lot of work to do, a lot of money to be raised, a lot of research to be done for prevention, early detection, and a cure, a lot of women to reach, a lot of understanding and insight to be had, and a lot of hope in this world. These women are an inspiration to others and when they talk people listen.

One of the participants who is in early retirement due to the side effects of her treatments reported how busy advocacy work keeps her on a daily basis:

I did the Relay for Life in '05. American Cancer Society, Lance Armstrong Foundation, Cure. It seems like I'm forgetting something important, but I don't know what it is. I just try to stay busy and I write letters too. I actually visited Washington, and visited the NCCS, The National Coalition for Cancer Survivorship in Washington. I went up there and did their day on Capitol Hill with them and actually visited in our senate and representative offices and our US representative signed on to our bill that we were pushing. Basically, it was the Comprehensive Cancer Care Act or something like that. Basically it's a law that would require Medicare to reimburse oncologists or doctors to keep one centralized file, medical record, when a person gets diagnosed. I think they've reintroduced it this time. But, it's a good bill. Right now, I'm in the process of trying to put my entire medical record together just with my PCP [primary care physician]. I had to do it for my disability stuff. And just recently, I had a review of my disability with CIGNA, the commercial disability, and it was a nightmare getting records. So that act would, you know, that would be a great thing to get through. The Anderson network...I volunteer for them [also]. I would do anything for Gilda's Club that they would ask me to do.

Another participant describes her advocacy tasks and how she looks upon her advocacy work as a part-time job:

I started looking for every resource I could possible find to learn about the disease, to help somebody else. I got on the computer, and could have made my disease like a little part time job. I did some volunteer work. Actually, for the American Cancer Society I would drive people to chemo many times to Parkland. And -- and I did stop doing that a few years ago because it just got to be too much with the traffic and gas going up so much. The support group down at Baylor has been very important to me and I'm been real active in it. [Medical facility] has a little newspaper and I've written some stories or articles whatever in that. I participated in -- the support group actually wrote a book and it's called *Torch: Tales of Remarkable Courage and Hope*. And we got that published and our goal is to give it to newly diagnosed women that are in the hospital.

This next quote describes one participant's volunteer work in teaching medical students how to compassionately work with cancer patients:

We have this program called Survivors Teaching Medical Students, and we have one in [Texas city] and one in [Texas city]. I do the [location] ones. One of my friends who is one of the facilitators goes to both because she's in charge of the program here. And we were talking yesterday to the students. Three of us told our stories, and every one of us had a different story and different reactions and, and everything. And that's something that we emphasize in our little sessions, like the one yesterday. We tell them don't be real negative. Try to be as positive as possible with patients because when you get hit in the face with something negative like that it's, some people would probably just fold their tents and say, 'That's it.' Fortunately, I'm not that kind (laughs). Fortunately, if somebody says something like that to me, I'm more like, 'You want to bet?' (Laughs)

Another participant described her positive experience with the Cancer Center, and how she would like to share that knowledge with others:

I would like to help people like me that just have no idea. If someone had come to me in the hospital and at least told me. I feel sorry for letting another in here like I was. I'm a lot stronger and I overcame it. I can understand that they wouldn't even try to fight because they wouldn't even know what's going on and that's there help out there. There's help and there's organizations that will help you. They paid [some bills], the Cancer Center. They helped me with my insurance. They paid it. Paid my electric bill. They had all these little things, I believe, that were free. And they did some of my co-pays because I couldn't afford my medical. And that was like \$300. That's what I want to do...to be able to help women like me that just don't have the knowledge and nobody to tell you. You know, you have to read. You have to educate yourself then you can help others and that's what I'm trying to do.

5.5.3 Spirituality

This next theme is *Spirituality*. The participants used various words such as “prayer,” “scripture,” “the Bible,” “God”, “the Lord,” “Christ,” “church,” “church members,” and “spirituality.” Some were always immersed in spirituality and religiously oriented prior to the cancer diagnosis, while others became spiritual with the onset of the cancer diagnosis.

Many of them expressed gratitude to God for healing them or supporting them through their cancer journey and found comfort in daily prayer. They mentioned prayers for themselves and how much they appreciated when others prayed for them. Gifts from God included chemotherapy, financial, and being healed. Participants told of how they felt comforted by their spirituality.

The following quote is from a participant who expressed how important it was that other people prayed for her as she believed in the power of collective prayer:

Oh, it'll make you think about it. It'll make you think about things. I don't think it changed my general attitude. The only kind of religious or spiritual thing that makes very much sense to me is kind of the Unity way of seeing things, which they also call metaphysical or New Age Christianity. So, you know, I certainly prayed and asked for prayer and had an awful lot of people praying for me. All my tennis friends rallied, my work friends. They brought things to the house. The main thing I wanted was prayer from them because I think there may be something to people having the same thought going up there, you know.

This next quote is from a participant who expressed how touched she was when she discovered strangers she did not know were praying for her:

You know, I've really begun to heavily believe in the power of prayer because people that don't even know me would say, well, you know, I told my neighbor [and] she had her church pray for you or put you on the prayer list, and I didn't even know. It's been so long since I've gone to church and I didn't even know people did that and it just was so touching and, you know, I think that gave me hope.

The next quote is from a participant describing how out of character it was for her to ask others to pray for her and how she felt propelled down the aisle of the church and received the laying on of hands:

Well, the thing that got me through all of this was my faith. I have many testimonies, many things that happened when even sitting at my kitchen table bawling and then on the TV is a commercial with Texas Oncology that I have never seen before and it had these women and people walking around in the commercial and it said, 'Cancer patients.' And then all of a sudden that went away and it said, 'I can survive.' So it was like OK I would suck it up for a while and then other things would happen. I believe in God, Jesus Christ, and everything. There were several things that, you know, strengthened my faith along the way that helped me. I had never in my entire life ever called anyone and said, could you pray for me? I was diagnosed on Thursday. On Saturday, I picked up the phone and made my first phone call and that's what did it. And I think on March the 11th I went to church on Sunday with my sisters and my niece at her church. Sunday before my surgery on Tuesday, and I didn't know anything about this church. I didn't know at the end of it that they did prayer call or anything. The next thing I know, I'm walking down the aisle, which I had never, ever done, but I just felt like that something was propelling me down there to do that, and I went to this lady and the next thing I know there are all these people around me, and she was praying and everyone had their hands and I felt like at that moment, at least, that my body was healed, and I think that, you know, [Doctor's name] you know, finished what God had done. That's what I think.

Some participants felt God gave them different gifts, and one participant describes chemotherapy as a gift:

I've had non-stop chemo. I actually tied a purple bow around my pole because it is a gift, and my nurse said, 'What are you doing?' and I said, 'Are you kidding? I'm trying a bow around my pole. Chemo is a gift from God to me,' and she said, 'Really? Could I keep your bow?' She said, 'I think other people would want to use it.' So they have my personal bow on my pole as a 'gift.' It just has enabled me to stay here and be a part of things that I wouldn't have been, so I've been very cool with it.

The next quote is from a participant sharing her view of God:

I feel like God has me here for a reason, and God didn't promise everything in your life would be smooth, just promised that he'd be with us, if we trust [Him], you know.

But not everyone was always happy with God, as indicated by the next participant who describes her feelings after a recurrence:

I've probably done more living, you know, in the past year and a half than I did before. And I lean on my faith a lot, although I will tell you that I got kind of upset when I had my last episode, you know, at the end of November and December and, again, that was when my mom passed away and all of this other stuff. Prior to that time, I was reading the Word daily and spending a lot of time appreciating my spirituality and really working on it and enjoyed it—flourished in it, I guess. And I've kind of backed away since. I got kind of mad at God for letting these things happen to me. I've not gotten back into my daily habit of the scripture. I'm not mad at Him anymore because, you know, it's just one of those things.

Another participant describes how a simple gesture from a beloved friend represented spirituality to her, and gave her a positive outlook:

[Friend's name] is a very spiritual person, and though I wasn't a very spiritual person, she introduced that to me. She came over like early the next day, and she had taken rocks, and on each of the rocks she put something, a word—Believe, Hope, Sunshine, and it was in a beautiful [inaudible] and she gave it to me. And she said, 'Each week, pick out a rock and just think of that word and how that word can help you, that week' and that really helps. It helps you not to focus on the cancer. It helps you to focus on that there is hope with that cancer or there is a belief that I'll get better—that really helped. It's one of the things that helped her [and] once you start looking at the hopeful side, the positive side of it, you start feeling stronger inside. It's like I can beat this, and it's worth beating it, because there is a better life after all this.

The following quote is from a participant who shared that she always believed in the Bible, but it took her cancer diagnosis for her to start embracing her spirituality:

Cards and letters and books is what kept me going, and I started getting spiritual again with the Bible, and that's what got me through—it actually what got me through it. The doctor had told me if I didn't have the surgery that I would only live seven months, and he said it seems that they got all of it. So, you know, I decided that I needed to change my direction in life. I always believed, but I

never really practiced and so the whole time I was sick, [I was] was just reading the Bible every day and other spiritual books that people brought me.

The quotes from this *Spirituality* theme compliments some elements from the next theme which is *Complex Support Systems* and refers to the support from a variety of people and places.

5.5.4 Complex Support Systems

The fourth theme, *Complex Support Systems* has to do with support from beloved people in the participants' lives as well as from people whose support came as a welcomed surprise. The word complex has to do with the concept of complex versus simplistic. It has to do with the "It takes a village" analogy, in which all members of a community are vital and helpful to each other. If "it takes a village to raise a child," then it takes a layered complex support system to help a woman with her cancer diagnosis. Everyone's help and support is vital. The participants had many people who they felt supported them through their cancer journey. The women spoke of supportive husbands, boyfriends, partners, mothers/stepmother, fathers, sisters, brothers, children, grandchildren, friends, church members, therapists, co-workers, support group members, chaplains, neighbors, bosses, doctors, nurses, other medical staff, cancer support communities, cancer survivors, and strangers they had never met before. One participant included her yoga instructor as being supportive and important. One participant mentioned how her dog was part of her support system because it gave her comfort.

All of the participants shared the importance of having all of these people in their lives and how much they appreciated the love and support they received. Some were supported physically after treatments while others had their entourages for their medical and chemotherapy appointments. Grandparents gathered strength and joy in their relationships with their grandchildren. Phone calls, voicemails, e-mails, visits, poems, cards, gifts, company at the chemotherapy appointments, and rides for treatments were appreciated by the participants. Their networks encompassed many aspects of emotional and social support, and they shared how much their network of personal relationships meant to them. For all of the women, their relationship networks were a high priority in their lives.

One participant talked about how supportive her boyfriend was during her treatments:

My relationship with [boyfriend's name] actually was very good and got better. I met him two years into having cancer. The first year was fantastically great; the second year, like all relationships, it was a little lackluster. It was kind of everyday life and kind of figuring it out. And as soon as he found out I had cancer, he lived in [City and State], he was great. He came back for seven of my nine chemos and stayed all week long, and picked me up and brought me to the bathroom and cleaned me up, and that's why I'm here now. He stuck with me the whole time, which I think is pretty remarkable, because a lot of people would have left.

The following quotes are from three participants who shared what they found meaningful or helpful within their own support systems:

A nurse practitioner. They knitted a shawl for me....and they all prayed over it. I always covered myself with that when I was feeling bad, and it was like it really helped. So things like that people did. People out of nowhere that I really didn't know did that. Then a guy, [male friend's name] he and I are real close; he

worked for me. And his wife, [wife's name], had breast cancer, and they came to visit me a lot at the hospital. My dad didn't like company; so nobody came to see me there, because he's very, anybody who knows my dad, that's just the way he is. So the three months there it was hard, because I didn't see anybody but I got a lot of cards and those cards meant a lot. They got me through a lot. And people from work. I kept them all, and I wrote a thank-you note to all these people. When I went back to work, I told them, you don't know what those cards meant to me. They lifted my spirits. And that was so sweet. The people that I didn't know really cared [and that] meant a lot to me. That's what helped me.

The day before I left work they gave me an envelope that had a letter to me and, it just said that they were going to be praying for me, not only individually but corporately. I work for a corporation and everyone on that team had taken verses from the Bible that they wanted and typed it, and then the prayer that they actually prayed, they typed it out, and it was very uplifting, inspiring, and very strong. And many times when I was, you know, feeling sorry for myself, I would take that, and I had every card that anyone sent me, and I would take that out and I would re-read it and when I was done, I felt better. And my daughter's mother-in-law, about every week she would send me a card of some kind. She does a lot of prison ministries and different things and at the time I didn't realize that what she was really doing was being a Chemo Angel. Now I am [a Chemo Angel] for someone else—an official one through a company

She [a counselor] helped me. My friend, a girlfriend in Vermont helped me, whether it was on the telephone or e-mailing, and she would come down to visit me maybe once a year. My support group ladies were helpful. The chaplain at Baylor was very helpful. I just sought out whichever one of those that I felt like, would, you know, was going to be there for whatever particular problem I had or felt, or if I was depressed or anxious or whatever. And one of those, the counselor, my girlfriend, the support group, occasionally my husband, my sister, my son would be there.

5.5.5 Support Groups

The participants in this study belonged to various cancer support groups, including gynecological, ovarian, or general cancer support groups. Sometimes the women started first in the general cancer community before discovering a support group tailored to their diagnosis. Sometimes they just began their own support groups when

they could not find one. The women reported they received emotional support, knowledge, encouragement, and mentoring from their relationships with a group and its members. The participants noted that they are able to talk about cancer and death/dying issues with the members of their support group, and that sometimes their family members did not want to discuss such issues. The women viewed their support group members as being part of their family or “sisters.” First, they learned from their mentors, who were usually seasoned group members, then they in turn began to mentor and “pass it on” to new group members. The women encourage the new members not to give up, have faith in your medical team, get support, that miracles do happen, to become educated about the cancer, and that there is hope at support group meetings.

One participant described the mentoring experience in a support group:

I was like a little puppy dog. I followed these women around. I just listened to everything they said. There are several. I mean I can just go through the list. I got an address list because we had exchanged phone numbers and addresses to call each other and stuff. And if I was to go through it [the list] with a highlighter, I know half of those women are gone. But I’ve learned so much from each one of them, whether they were older, or younger, or shy, or you know educated, or not educated. I learned from each one of them. And then, you know, I was able to kind of put it in own little file cabinet, pea brain as it is, and then pass it on to other women. That’s what I feel like part of my job is now, to pass it on. I was just getting ready to start chemo and there were probably about five women in the group at that time. And there was an older woman in there who was real nice and said, you know, if you want to call me, here’s my phone number. So I called her the next day and went over everything with her. What do they do to you? Where do you sit, and what does it feel like? Do you get nauseated while you’re sitting there? At each chemo, I found out more information from talking to people. I got very assertive about just going and talking to people and asking them things. The chemo that I did the first that first six months was like about a five to six hour deal. So, during that time you got to eat and drink and get up and go to the bathroom. Well, if you have a dress on, a loose fitting dress, it’s a lot easier to get in that bathroom and get your pants down and do your business and everything. Somebody told me that. And then

as I learned about the drill, so to speak, then I would kind of pass it on to other people.

The next three participants highlight the importance of having people to talk to about the cancer:

I need people that will talk about the cancer, and what it meant to them and where you go from here. And not that I ever want to get it back again but I want that information and want the knowledge that they have, and that's what's different. And the support group at UT Southwestern has just started, so who knows where that will go, and Fort Worth, I really hope we start one, and who knows where that will go. But right now, Baylor...I like those women, I really do.

I would like to go every Monday, but I can't. And the Mondays that I don't go, you know, I suffer, not because I'm depressed. I mean, I care about these women. They really are like my sister, my mother, my aunt. So I think it's important that there's a lot of women that have ovarian cancer in Fort Worth that aren't getting any [support], who are just sitting in their home just like I did. When I came back to work, everyone said, okay, you're through with your chemo, and you're going to go back to work and everything is going to be normal. Well, I went back to work and it's not normal. I'm still crying, I'm still, you know, worried about this. Now I'm frightened about when someone says the word, recurrence. And I just happened to go to a meeting one time and I didn't talk about it because my family was sick of hearing about cancer. They didn't want to hear. I mean, I talked about it obsessively, and then I get with these other women and they were always talking about it and all of a sudden it's like everyone talks about it. And so now, I just tell my family, I'm talking about it and that's that, you know. And I'm just sorry that there's women who act just like me. And as compassionate as my family is, you know, I don't get the emotional support I need, that I get from these women because they don't know. So it's very important for women to find a support group. That it's not women sitting around crying about their cancer; we're laughing and talking about it and planning trips and, you know, it's like good girlfriends.

Here at Gilda's Club I came to the support group every week. I would meet people at different stages. People still going through chemo, people just finishing chemo, and everybody knows what you were going through. And that was really good to be able to talk to people going through the same thing.

Another participant described how the support group is important in normalizing the distressing emotional experience of having cancer:

When I started going to support groups it helped, because these girls were feeling what I was feeling and everything I was going through is normal. I didn't think it was normal but it's normal.

One participant described how some people have preconceived ideas about support groups, and how many newcomers express surprise and happiness.

We have lots of friends, balloons and food and laughing, and everybody, to a person, that comes into that group, goes, 'Wow.' There's an African-American gal, this is her second week, last Monday, and I said, 'I wasn't here last week. I'm so glad you're here, and I want your story and all that stuff.' And she goes, 'Man, I'm telling you, they said come to a support group, and I said, 'Oh, no, don't make me do that,' and she said, 'Well, what's the problem?' And she goes, 'Are you kidding? I thought I was going to come in and there was going to be this roomful of sick, depressing people. Everyone is so pretty, and everyone laughs.' We do have more fun than you would ever believe would be possible, for what we are there for.

5.5.6 Chemotherapy Side Effects

All of the women in this study received chemotherapy. The sixth theme, *Chemotherapy Side Effects* varied depending on how many chemotherapy treatments a woman received. Some received chemotherapy for a few months while others received chemotherapy for several years. Chemo treatments ranged from several to 108 treatments. One participant had been on chemotherapy off and on for seven years due to multiple recurrences. The participant with 108 treatments had been on chemotherapy almost continuously for five years.

Each of the women reported that chemotherapy was an emotional experience for them. Chemotherapy was scary, partly because as they did not know what to expect. They reported that the side effects were difficult to bear, and for some it literally brought them to their knees with nausea and vomiting. Side effects included hair loss, fatigue, weakness, lack of energy, sleep disturbances, concentration problems, constipation, neuropathy in the feet and hands, tingling in hands and feet, low blood counts, hives, insomnia, nausea, vomiting, painful joints, deteriorating bones, muscle aches, trouble breathing, skin issues, decrease in socialization, changes in the sense of taste, weight gain, dizziness, blisters on feet, sleepiness, anemia, restlessness, inflated stomach, neuropathy in the ears which sounded like crickets and grasshoppers, ringing in the ears, hot flashes, short-term memory loss, lymphedema, deteriorating eye sight, a decrease in hearing, loss of eyelashes and eyebrows, “chemo brain,” broken bones as a result of passing out, low blood pressure and a racing pulse, which required immediate oxygen.

For each type of cancer and cancer stage, a certain number of chemotherapy treatments are recommended to maximize a cure or remission. For some of the participants, they seriously contemplated stopping chemotherapy early due to the side effects. The following quote describes one participant’s experience with an IP chemotherapy treatment (IV chemotherapy is done through the vein and IP chemotherapy is done through the abdomen):

I was in the bathroom. I had just had my first IP, and I was crying and told my daughter I couldn’t do it, and would they forgive me? I couldn’t do it anymore, and then she started crying and said, ‘Okay, I’m going to tell you that you’re

cancer-free.’ So I was in the bathroom like on the floor, and she was trying to help me talk about it now, because at first we were bawling, and then we were laughing because she couldn’t get in [the bathroom], and I couldn’t get off the floor. I was like I felt like I was like in a Baptist church. I was like, ‘I am so yours.’ I wasn’t doing that, but that’s how I felt. And then I said I could do the last two treatments. I’m sure some people would have said, ‘I’m cancer-free. I’m not going to do them.’ but everything that I read, everything I read said that was my best chance, and your best chance is the first time. It’s not your second and third time. It’s your first time, so I just said, ‘I can do it, I can do it, I can do it,’ and I really wanted to live.

Another participant describes her difficult experience with chemotherapy treatments:

I was supposed to have seven sessions, but I only did six because, it was just too much. I just couldn't take another one. I was so sick. –It was just getting to me where I just couldn't handle the chemo. And when I told my doctor that I didn't want any more chemo, he said that I was doing so good, so I decided, well, I'd do one more if that's the case, you know. But I thought if this is the way it's going to be all the time and living like that. I was in pain, you know, and just sick all the time. There was no peace. I couldn't sleep and [it was] going on for six weeks like that. It was hard. So then he gave me encouragement like you're doing so good, you know. The CT scan shows this and your C125 is going down. And that gave me encouragement to just keep going that that you have to go through it. It's worth it. But if they tell me now you've got to go through six or seven more sessions, I don't know if I want to do that. If it prolongs your life, of course, you want to, but if you're going to be sick doing that all the time and never get to do anything and have someone take care of you, it's just hard. I'd rather live being able to do something and be with my family and then go somewhere instead of laying in bed, you know.

One participant describes the side effects of chemotherapy:

Oh, lord, maybe the loss of hair, and you do the nausea, which is horrible. You have such restricted activity. You have days that you just — you cannot. It’s not about people who go, “Oh, you’re tired?” No, low on gas is not it, you are out of gas. There’s just no way to go. There’s neuropathy with hands and feet. It’s just horrible. Your skin takes such a beating on this stuff. The side effects are horrendous. My gal that’s on Caring Bridge gave me a wig, and she has given me another one. It’s frosted blonde. I was a redhead all my life. It’s a blonde

thing, and it's been very different for me, but it works. But now I've decided something is coming in, so I just let it come, but the hair thing is real big too. When you have to go and get your head shaved, the first time I did that, we were sending troops over to Iraq. The guy that does me was up on Northwest Highway, and, he said, 'I'm doing a lot of guys in the reserve base that was next door,' and I said, 'Well, shave away, because I'm going into a war of my own.' He said, 'Yes, you are.' So then when I had to have it done again, a couple of years ago, I went back up to him, and he did it again. And I think the second time was harder for me than the first. Yeah, and this gray thing is not me. I'm not gray.

One participant described the lack of privacy and the suffering that takes place in the chemotherapy room:

Another thing I'd change is all these people in the room where you go and have chemo. All these people are in folding chairs, and there's a row and then a row and you face each other. Well, you know, when you've got your port right there, and they're pulling your shirt down and you've got some man sitting across from you, you know, the first time, it was like, excuse me, you know, I'm trying to pull. And then at the end, I didn't care, you know. It's kind of creepy when you have these men, you know. I think that it should be separated. And some people are just drawn to—oh, what are they doing? You know, just staring and stuff. Have you ever been in chemo rooms? Okay. So you know that when you sit down, and they're doing all this stuff to you. So if they have to stop and tell everyone, could you go outside? You know, the person sitting over there, he's sitting with his wife. He's not going to get up and go outside. So really there's no way to overcome it, but I just find it a little creepy. Because I'm not used to, you know, exposing [myself]. They didn't see anything, but when you've [have] this pulled up because my port was right there, and then they're going to bruise, one, two, three, pokes, you know, and so they're jabbing you. But everyone in that room is suffering. Whether you are a patient or if you're a nurse, [you're suffering] because you're hurting someone, and you know you're giving them this stuff, and they're not going to feel good, so everyone is hurting in that room—just different degrees.

Most of the participants brought up their memory problems, which are a common side effect of chemotherapy. This was evident during many of the interviews

when the participants had a word on the tip of their tongue, but could not conjure it up right away. Many of them have seen improvement with their memory over time.

One participant described her ostomy and memory loss:

I, sometimes I think, especially since I had to have the bag, I think, gee there's so much artificial on me, you know, this port, this bag. Where is the real me? [Laughs] But I try not to dwell on that, and I remember that I'm still, I'm still me, and I still have a certain amount of brain power anyway. Although I do have chemo brain sometimes. I can't remember what I'm talking about. You know, mainly, it's like there's this word I want to drag up or there's somebody's name, and I can't remember it to save my neck kind of thing.

5.5.7 Longevity

Longevity encompasses many aspects of time and length of life. When the women received their cancer diagnosis, they had thoughts of death, believing cancer equated to death or a death sentence. They were scared of death and wondered how long they would live, and if they would die. Wills and inheritances were discussed. They spoke of their oncology friends, mentors, and support group members who had died. For the ones who were cured with no recurrences, they reported concerns about if and when their cancer would come back. Some reported they when they feel a twinge of pain, they worry the cancer may be returning. For the ones with metastatic cancer, they wondered how much time they had in the future and shared how they wanted to enjoy each and every moment no matter how long or how short.

A few used humor when speaking of their longevity in the interview and reported joking with friends and co-workers about death. For some, plans such as traveling, buying new clothes, and joining the Peace Corp were put on hold. At the

same time, some participants did things they would not normally have done, such as give their children an early inheritance to buy a new home or adopt a newborn or purchase a new car. They felt it was necessary to enjoy these things now while they were able, because they were unsure of their duration of life and they wanted to live in the moment. For others, they did not do anything out of the ordinary and just wanted to spend time enjoying the everyday things that gave them pleasure, such as listening to a grandchild tell about her day on the way home from school.

One participant said she felt good when a nurse told her she was on volume three of her medical records, and the nurse was proud of her. This was an important moment for the participant because the nurse told her that most patients with her diagnosis did not make it to volume three. A few mentioned how their medical staff had advised them that their cancer was seen as a “chronic” condition and would be treated as such. Those participants reported it gave them a sense of comfort that having cancer is not a black or white issue that it is not just a living or dying issue, but a question of how a patient wanted to spend their time while dealing with this chronic disease.

After diagnosis, many participants were overwhelmed and felt the need to make legal and funeral arrangements since they didn’t know if they would be well enough later. The following are quotes from three participants:

When you are told you have cancer everywhere, you just kind of think, oh. I guess I need to see my attorneys and make sure I have everything in order. That's the main thing. And, of course, you don't know what you're going to do. You are faced with a lot of decisions, and having to suddenly be an expert so

you can make all these informed decisions about things that are going to affect your life.

I was already planning my funeral because I'm like, I had one deadly disease and my stage, you know. I know there's no cure, and the recurrence [chances are high] when you read the percentages.

I had some real ups and downs. I felt, you know, it was a real big blow, and I had thought that I was not that ill, and then all of a sudden the specter of possible death was there, and that was kind of frightening. Of course, physical pain always makes [chuckles] emotional pain, too.

One participant recalled looking up her diagnosis statistics online and her reaction to the information:

So my surgery was — I found out the 13th, my surgery was November the 4th, and I found out about a week after that what stage I was—like stage 4, like 95 percent of the people die. So it's really a hard month, that first month is really, really hard. You want to have a lot of hope, but your hope is very little. Like I had an end-of-life talk with my kids. I told them where all the stuff was, and all the paperwork, and I told [her ex-husband's name] how to go through all that.

Another participant described how she was not interested in cancer statistics:

I really wasn't real interested in statistics because I figure that they're not me. I'm not dead, and I think I'll do better than those people did. And so I had a more positive expectation, I think, than negative and I just tried to stay rational about thing. With all the cancer in the family, I tried to inform myself somewhat and I just felt like, well, I think the bottom line is that whatever happens, I will get through it. If I die, I'll get through it. If I live, I'll get through it, and if it's my time, it's my time.

Two participants who were cured or currently have no evidence of cancer, described their thoughts about having a recurrence:

How do I know that it's important to call a doctor's office 'cause I'm not, you know, I'm not one to just call, oh, I have a pain. I mean, right now I do worry. What if the cancer does come back? I try not to think about it, but I do, because I still have some pain. When I brought it up at my last doctor's visit, he said that it should go away. You know, patients have pain, some patients have pain after surgery, but they've never complained about it three to five years out. And so a part of me is like, okay, that's what he's telling me, and I believe him. But then another part is like, well, what if it was like that original doctor who said that I was fine and I really wasn't?

There were times that I was worried. I would just be driving down the road and I would see myself [and] my doctor saying, your cancer is back. I would even see myself having certain facial expressions. I mean I was planning it, and then once I would see that was happening, it was just like, stop it. I would just say things out loud [to myself].

Three participants whose ovarian cancer is considered chronic and who have had one or more recurrences described their thoughts:

I asked him, 'Will I be here for my birthday in July?' and he said, 'Oh, yeah.' So you don't think very far out. You don't buy new clothes. [Her friend's name] would say you don't even buy a new tube of toothpaste until you get a little time under your belt where you go, okay, maybe there is going to be something. And one of the first things the nurse told me in [doctor's office] was, '[Participant's name] this is a chronic disease now,' and I said, 'Really? Uh, all right.' And that was helpful to me, to think of it as chronic rather than I was going to be Gilda Radner and go out looking pitiful. It was real important to think there might be something else. You know, once you've figured out about death, then you're ready to live, and I'm not sure you are fully, until you do. So that was good for me, that was a good thing to do, and it was a comforting thing, to think I'm going right back over there with my mother and my daddy. That's way cool. That's my favorite people in the world, and I like that. And one of the gals that is in hospice right now called a couple of weeks ago. I was shocked to hear her voice, and she said, 'I want to talk to you,' and I said, 'Okay,' and we talked and she told about giving her fur coat away to her best friend and how she'd been able to make Christmas, and that was a goal of hers, and her grandchildren. And then we talked, and then at the end, she said, 'Okay, and I will see you on the other side,' and I said to her, 'Oh, no, you don't. I may beat you there, and, in that case, I'll see you on the other side, and I will save you a place,' and she laughed. Well, there is something very wonderful about being

able to do that, do something that many people shy away from. There is something very wonderful about knowing where you're headed, yeah.

The nurses in the chemo room. I had my favorites, and I usually try to get them and they, they'd laugh and joke. The one that I really get all the time, her name is [nurse's name] and she, she said, 'You know, we're starting volume 3 of 3 for you.' She said, 'You know, not that many people get to go to volume 3 of 3. They either get better and, get out of remission or they die.' And so she just said, you know, she was so proud when she started volume 3 of 3 for me. My doctors the first nurse that she had was a real kind of just tell it like it is pull no punches and she said to me one time, 'You know, we're not going to cure you. You do know that' and I was like, you're not, you know. This was like after I had my first recurrence or something. She says, 'What we're going to do is try to keep you alive as long as we can. We're going to treat cancer like it's a chronic disease, just like a diabetic gets insulin, and so you're going to have to probably be on chemo the rest of your life and you just have to accept that but, you know, just tell yourself we're going to treat it like chronic disease and look how long people live with chronic disease.' And I thought, well that is kind of a good thing, you know, that kind of gave me a perspective on that. I'm going to either live or I'm going to die, you know. It was like in between. I was going to live and that was going to be maybe a little unpleasant. I had to go take chemo, you know, once a month. You know, maybe have another surgery and maybe this and maybe that, but at least it gave me a little ground, it wasn't just all black and white. It wasn't, I'll live and it's never going to come back, or I'm going to die. So I think that was one thing that she said to me that stuck with me.

When I re-diagnosed, again, I kind of took another look at my whole life. My son and his daughter had been married for a few years, and they had been trying to get pregnant. It's awful to go and read crap on the Internet, but when I was re-diagnosed there's this magical number of six months. Because if you can make it past six, be in remission for more than six months, then you are considered to be platinum resistant, which is a bad thing because platinum is one of the big drugs that they use to, combat this. So if you are platinum resistant, statistically your chances of living another 18 months are like 10 percent. So when I was re-diagnosed, and it was kind of at that, you know, seven months, which is depending on what calculator you were using when they actually started counting you being in remission. I kind of took stock of a whole lot of things and kind of rearranged my life to where I was going to enjoy what time I had left. And, anyway, my son and his wife had been trying to get pregnant and I decided that instead of me leaving my money and stuff to my kids after I died that I would much rather let them use some of it now, so, they just adopted a

baby. That was fun. She was born [date]. So anyway last year, I spent some of my [laughter] kids' inheritance, and I gave my son and his wife \$20,000, so that could help them adopt a baby, and I gave my daughter, \$20,000 so she could buy a house. So I had lots of fun doing that. I just can't tell you how much fun this has [been], helping, participating in the house hunting and looking for things. I don't know, it's just been incredible. So, and that's kind of a weird thing. That's a monetary thing that they certainly weren't expecting. But it's been nice for me to enjoy that, as well.

5.5.8 Personal Growth

Personal Growth includes what the participants perceive as the benefits cancer has given them, their insights into life and relationships, and how having cancer has changed them for the better. As one participant reported, she got “the wakeup call.” The participants reported good things have come from having cancer which had a lot to do with their personal relationships and roles which included: seeing life differently, not taking life for granted, being a better person, a better business owner, a better girlfriend, a better wife, relationships with siblings and friends were strengthened, relationship with child/children are better, other relationships flourished, a family was reunited, relationships were fixed, marriages were stronger, having the ability to get rid of toxic relationships in their lives, communicating to children about anger and problems now and not holding back, and pushing family members to get genetic testing.

Participants reported changes in themselves, such as they are more assertive now, more outgoing, more outspoken, more confident, more sympathetic, more loving, and more gentle. They reported life is better now, their faith is stronger, and decisions are based on the cancer now. They are comfortable saying “no,” are taking care of themselves, and not letting the small things get the best of them anymore. Participants

reported they feel they are cutting people more slack, have a better attitude, are nicer now, more happy, and are able to ask for and receive forgiveness. They feel cancer was a blessing as it has enriched their lives and relationships and has brought them to volunteer work and advocacy work, which in turn has helped countless others.

One attributed cancer as being the gift that has kept her from going back to using drugs and alcohol:

I'm such a better person now. I love myself now. I love my body and my hope is to help others. To become an advocate for the cancer awareness people—women. Mostly, that and help people who are on drugs. That's part of my history that some people don't know, and I don't tell too many people.

One participant shared that her family was in state of disarray and her cancer diagnosis helped the family back together:

So if I had to do it again, I might do it again. I know that sounds really bizarre, but I don't know if it would have [come back together] without this, without something that was life-threatening like this. I'm not sure that my family would have all gotten back together again, you know? But this made everybody realize what is important in life.

Another participant shared her positive perception of having had a cancer diagnosis:

I think now I look back on it and I see all the good things that happened from the cancer because I've changed. My life has changed completely. I don't know that I had really any loss, but I had some regrets about a couple of things that I did that I look back and probably should have done in a different way, but at the time, I couldn't really help myself. I think my life, it's probably a cliché, but I think my life is better. I'm a better person. My home life is better. My outlook on life in general. I've had a lot of benefits from cancer. So I'm sitting there crying and I had a journal and I was writing some things, and I flipped over and there was that paper that I had written all of that stuff, and I was reading it, and I was like, oh, my gosh, that happened, this happened, you know. I wanted a stronger marriage. I have it. I wanted to be closer to my kids, and I

have that. All these things. I wanted to have a stronger faith. My spiritual life I wanted it to change and all of these things checked off, and it's happened now. Do I wish God had done that a different way? Of course I wish that it would have been different, but this is the way I got it.

One participant described how she has become more assertive in her medical care and in her personal life:

Since I was diagnosed with cancer, I have a lot more moxie. I say the word in support group. It asks what if you, you know, how's -- how's cancer changed you? And I -- I said well, I gotten a lot more ballsy. And this older lady just kind of went -- [Participant's name], let's say assertive. And I said, whatever you want to call it (inaudible), moxie, ballsy, assertive, I'm a lot more than I used to be. [Interviewer asks for examples]. Let's say they made me wait too, or they didn't, you know, I never would've double-checked somebody, but I do that all the time at the hospital now. When they draw blood, I'll say, I'm supposed to be getting CA125 today is it on the order, you know? After I let them draw blood in the past and, they forgot to do the CA125. Well, I used to not rock a boat, or not question anybody about anything and now I do. I'm very polite when I do it I'm not rude to anybody or mistreat anybody. I'm just a lot more assertive in every way. If I go in a store, there's a pillow and it's got something on it, I'll go find the manager and say, would you take some off the price of that pillow. I would never do things like that before. I walk up to people in the hospital and start talking to them. I say no to people a lot more. Before, somebody invited me somewhere and wanted me to do something. My instinct was to always say yes and then stew about why did I say yes? How can I get out of it? And now it's just the opposite. I'll say, no, I don't really think so. I'll think about it, but I don't really think so. And I think everybody around me has noticed.

One participant describes how she has become more sympathetic due to having cancer:

I've made some good friends. I'm more sympathetic towards people who aren't in great health because I understand where they're coming from. Whereas before, I really didn't think much [chuckles] about my health because it's always been really good. I've never had any kind of health problems, I thought somebody might be having heart problems because they don't take care of

themselves Anybody could become ill at any time. So just being sympathetic more towards others and doing more volunteer work.

5.5.9. *Bonded with Doctors*

The eighth theme, *Bonded with Doctors*, describes participants who like and trust their doctors. During their cancer journey, they encounter many types of doctors including, internists, obstetrics and gynecologists, gynecological oncologists, and oncology radiologists. When the ovarian cancer participants or the participants who had undergone extensive cancer treatments spoke about their doctors, they used words such as “love,” “hope,” and “God.” Having a good relationship and rapport is important, especially to the participants who spend a great deal of time in and out of a physician’s office. If the women did not like or trust their doctor’s skills they moved on to other physicians whom they felt comfortable with. The ones who are cured or who are in remission feel their oncology doctors’ skills are directly responsible (with God’s help). The ones with metastatic cancer or who have a recurrence get encouragement and hope from their doctors and listen intently to what the doctors say at all times. The oncology doctors who are highly favored and bonded to are the ones who are confident, honest, and maintain hope.

One participant [quote one of two] described how her doctor was a good fit for her:

Everyone said, ‘Get [Doctor’s name]. He doesn’t have the best bedside manner, but he is the best surgeon, by far.’ So I said, ‘I need to have [Doctor’s name].’ He came in, and he didn’t have a good bedside manner, but he looked at me and said, ‘I will cure you. Cure you.’ And I’ve heard, since then, he doesn’t do that to everybody. So he felt confident enough that something was going on with me

that he felt like he could make it work. So I got him, and I'm really glad. I love him, love him. Like I said, [second Doctor's name] is great, and [Doctor's name] is just very business. This is what you're going to do, 'If you're going to survive this, this is what you're going to do,' and he says it with such conviction that I just felt like this is what I'm going to do, and I think that's why I'm sitting here today. I think he saved my life. I think if I didn't have him, I might not even have survived the surgery. From what I understand, the surgery was pretty touchy. So I think I was in very good hands with him, and, like I said, I think, for me, that worked: 'This is what you need to do.' I'm very good with that kind of thing instead of, well, to sugarcoat things—[it] wouldn't have worked. You know, as soon as I knew what I had, it's time to fight it, tell me how to fight it, and I will do everything in my power to fight it.

One participant whose condition is chronic described how important her doctor is to her and how she will never ever leave him:

I never heard the word terminal. I never heard those words, and my doc, one of the first things he said to me was, '[Participant's name], this is not hopeless,' and, see, I'm kind of a hopeful person anyway, so that was good for me to hear from my doctor, and I remember being in the 33 or 34 number of treatments, and everybody else would sit in the group and talk about their 3 to 6, how hard it was. And I would laugh with him, and I would say to him, 'One day, will my body just say, we don't want any more?' and he said, 'Uh-huh, uh-huh.' He said, 'Not today.' So he's like that, and he's also so well respected and not only for smart, he's not just smart, he's the most compassionate human being. I mean, he sits on the bed and cries with those gals when he does surgery and has to tell them. He does, he's probably the best in the whole world, and, so I had a good doctor that established that it was not hopeless, because I really do believe you're not supposed to run out of hope, and I think he's been wise. In December, when he called and put me on this oral thing, I said to him, 'Now, you understand this right now. I'm not going on any trial, so don't even be thinking it. Don't speak it again. You have got to always be my doc.' And he said, '[Participant's name], I'm going to always be your doc.' You know, he said, 'Remember, when I told you about that first trial, I told you you would have to come have coffee, because I would need my [Participant's name] fix every week,' and I said, 'Well, okay, just so you understand that I'm not going anywhere.' He said, 'I got it.' So, to know that he's committed to me, and for him to tell me it was not hopeless in the very beginning...

One participant's described how her doctor has the ability to work around events in her life:

But my doctor, I, I love him, he says, 'Want to take a trip? We'll work around it.' So [laughs] we worked around it, and I went on that trip.

One participant described her radiation treatment and her radiation oncologist who she holds in high esteem:

I remember [Doctor's name] saying, 'We're going to give this thing a run for its money.' Because I told him the whole history, and I told him I thought it all went back to that rape, and then he looked at me and he turned red in the face. He said, 'That bastard.' So we kind of bonded. I really did love that guy. He's a great guy. He helped me a lot just with a lot of reassurance and, early in the radiation and chemo, he examined me and said the tumor is responding, and so I felt early on he was always honest with me and, if he didn't know something, he would say so. He always took time to talk to me. That's what helped me is I felt like I was in competent hands—competent and caring hands. And that's the complete package.

One participant described her doctor's straight forward approach and focus:

[Doctor's name]. I just like him a lot. One thing I will say is he treats a patient, you know. This is what you need to do: you need to eat, you need to do this, this, and this. If you are depressed in the long run they say we are going to give you a pill for it and if you need support go get it but this is what we're doing—we're going to stay focused. And that was good because that was what I needed to do.

Another participant described how encouraged she felt after one positive interaction she had with her oncologist:

He said, 'So don't worry. Stable is a good place to be.' So I went home and was happy about that. I was worried, you know, he said, 'If you want alternatives. If you'd like me to let you go talk to someone about a bone marrow transplant, you're more than welcome to do that. But, you know, stable's good.' [Laughter] So, he's always saying the right things.

Some participants felt let down by their original doctors who failed to follow up with them when they were diagnosed with cancer or if they misdiagnosed them. This was particularly true when there was an established long-term relationship with the doctor:

I did share that with my gynecologist, [who said], ‘Try a different position.’ I went to him for 20 years, 20 years, and he’s the one that did my hysterectomy, and never called. I think that’s a pretty big deal. I mean, he knew I had ovarian cancer, but he never called to see how I was doing.

5.5.10 Medications

Medication addresses a large variety of ailments such as nausea, vomiting, pain, sleeping problems, hot flashes, low libido, depression, and anxiety. Many participants used anti-nausea and anti-vomiting medications to manage the chemotherapy side effects. For some it worked and for others it was less beneficial. Pain medications were also to also combat cancer treatments and their residual effects.

At the time of the interview more than half of the group reported they were on some type of psychotropic medication. One was taking Lexapro (escitalopram), two were on Effexor (venlafaxine), one was on Effexor and Ambien, one was on morphine, Fentanyl lozenges, and Klonopin (clonazepam), and another participant was taking Effexor along with an anti-anxiety medication. A seventh participant who was not on any medications at the time of the interview reported using Ativan to help her sleep when she had chemotherapy and had tried Wellbutrin for a month to try to revive her low libido.

Participants mentioned using sleep medications (Ambien and Tylenol PM were two mentioned by name) as well both at home and at chemotherapy appointments. Three of the participants also reported during the interview that the women in their support groups were all on some type of medication for coping and others took a lot of drugs during chemotherapy to sedate them and help them cope.

The women on the psychotropic medications described various reasons for taking such medication: Four women were on Effexor. Two of the women said they were taking Effexor to give them relief from their menopausal hot flashes, and they reported the added benefit was that it helped them with their moods. The third person was taking Effexor for depression, and the fourth reported she was taking it for hot flashes and depression. A woman taking Lexapro reported she never really felt like she was depressed, but decided to take it when her adult son became very concerned about her.

The following quotes are from six of the participants who share their medication thoughts:

I am on Effexor 37.5, for hot flashes, but Effexor is an antidepressant. Now, usually they give it at 75 or more, but it's a great thing for hot flashes, but I'm sure it has some effect on me and how I'm feeling. Now I don't get depression or sadness at this particular moment. Yes, I think I have normal amounts now. Prior to cancer, I think I've had some major depression and not known what it was.

My brain [was] telling me, worrying about this, worrying about that. Once I started taking it, I realized I really was depressed a little bit. You know, plus he told me it's going to really help your hot flashes. Well, I didn't believe him. I talked to several of my other friends that were on it, and they said they were taking it for hot flashes. I thought, okay. So, he tried a high dose, and I took

one and I felt horrible. I don't remember driving to work. So then he bumped it down. And at Christmas, I got off my schedule, and I was just weeping, a horrible time, and I knew it was because I'd gotten off taking them, so I started taking them again I think overall it helps me—the whole concept of my life. I wish I had started from the very beginning because I think it would have helped me during all this other stuff. I think I would have been able to cope with the chemotherapy if I had had the Effexor, and if I had known about support groups. If I had the women that I have now...

I still take antidepressants. I had gotten off of them and started taking herbal stuff, St. Johns Wort. And then read St. Johns Wort might - have an effect on chemotherapy and then I quit. I quit taking hormones [and] I started having hot flashes so [Doctor's name] put me on Effexor, which has really helped with the hot flashes and the depression.

So anyway, he was the one that took me for all my chemo appointments, and they would give me some Ativan. I would just snooze throughout the whole thing, and then I would half remember everything. I would just be in a daze.

Pain management...I'm still on significant pain management. And then I take some, a small amount of Klonopin for anxiety, mostly for sleep. I don't usually take it during the day. It's 0.5 mg to sleep. My morphine is a low level, it's not a very high dose, it's 30 mg twice a day. And then for breakthrough pain, I have an actual lozenge. It's a Transmucosal Fentanyl, which is Fentanyl 800 micrograms.

What's the name of that pill? Lexapro, I think it is --- because at one point, it was in January, around the time of the baby's anniversary of birth. And I was, you know, kind of getting the post-Christmas downs anyway. And my sneaky son [laughs], I was feeling down, feeling sorry for myself. I think I was feeling sorry for myself because both my kids were so busy that I didn't think they were giving me enough attention [laughs]. But I didn't want to say that. So [my son] called the doctor behind my back [laughs] and told him.

5.5.11 Counseling

Many of the women reported they participated in some type of counseling after receiving the cancer diagnosis, for various reasons. One spoke to a chaplain counselor multiple times because she became angry. Two participants were recruited by their oncologists to participate in a Ph.D. study about counseling. Another participant spoke to a pastoral counselor about her work-related issues because her employer expected her to work at full capacity. A fifth participant sought out a variety of counselors and psychologists after realizing she needed help in coping with her diagnosis, as she began to have nightmares and would sometimes break down crying in the car for no reason. A sixth participant sought out her old counselor who had helped her years prior with her divorce. A seventh participant saw a counselor as well. Another participant did not seek out a therapist or counselor as she was a therapist herself. She reported she used her REBT therapy skills on herself when needed and also was the recipient of a hospital's peer counselor. Another participant had wanted counseling after being diagnosed but due to lack of finances she had been unable to afford counseling.

One participant described why she sought the help of the chaplain:

I was just angry. And that actually scared me a lot more. I can deal with crying. I'm a girl, and it's ok for me to cry. The anger scared me because I am not usually an angry person. There would be days when I just wanted to throw things or slam doors. I'd be at work, and I'd get short with my co-workers and I'd have no patience. I didn't mean to do it, and it's not the kind of thing I would normally do,

One participant describes the difficulty in finding a counselor to talk to after she was diagnosed and the great lengths she went to get help for herself:

I was telling my friend that I was having nightmares that my doctor gave me a wrong prescription, or medication, or did something incorrectly during the surgery and kind of made things worse. And when I told her that, she was like you really need to go see a counselor or psychologist, and that she had gone to see one in the past and it seemed to have really helped. It was frustrating because when I decided, okay, I do need some help, I'm going to go talk to somebody. I went to see a counselor, and she wasn't very helpful, and didn't give me any type of advice. She just said the way I'm dealing with it or handling things is normal and to be expected and that was about it. I kind of felt like it was a waste of my time. And then I tried to set up appointment with another counselor, and he scheduled me for the wrong day. So after that, I wasn't going to go back to see anybody. Then my friend was the one who kept telling me, no, you need to go talk to somebody, go see a psychologist. Then I called my oncologist's office for a referral, somebody who maybe worked with cancer patients, and they gave me a name and number, but, but that lady was booked up for three months in advance. And so I'm thinking this is just not meant to be. [Laughs] So I just randomly picked somebody off of the list that was covered from our insurance, and he turned out to be pretty good. I went to go him a couple of times and then, I went to see three different psychologists, initially to see how it was. A couple of them were okay and the other one wasn't very helpful. The one that I thought was most helpful, I felt like he listened, he gave me feedback, suggestions, and then also his wife had been diagnosed with cancer in the past. So I thought, he had some experience with it.

One participant described how she used her divorce counselor from many years prior and would have preferred a counselor with an oncology background:

If there is an oncologist counselor who sees women all the time that are bald and hears them and knows that it's a common thing to be very depressed over losing your hair, to know what it's like to go up there and have to be hooked up to the IV and get stuck so many times and uh or to have a husband that's not real responsive or just all the different issues that come up with a cancer patients that my counselor doesn't really know because I'm her only cancer patient. I think she mostly treats married couples.

5.6 Depression

The women had each been through quite a journey with their gynecological cancer experience and at the beginning had psychological distress. I discovered that the study of depression or the feeling of being depressed is a difficult emotional issue in a retrospective self-report qualitative study.

Later in the interview when asked about any depression they had after being diagnosed with cancer (retrospectively), three of the women reported they had “mild” depression but only for a few days, or had “some” depression but only at night or had a “little bit” of depression, but it was not major depression after being diagnosed with cancer. Another reported she had felt “down,” but never really felt depressed. Another participant said she felt she had had a “little bit” of depression after being diagnosed with cancer then shared that she really did not think she was depressed at that earlier time. Another shared her feelings in the past after a diagnosis of emotional moodiness. Another reported she sometimes had bad days and felt depressed sometimes, but everyone has bad days she reported. Another reported she had depression in the past and when it subsided she took St. John’s Wart then switched to Effexor after her cancer diagnosis. Another participant reported she never felt depressed but had allowed herself to grieve and to do grief work. Since depression was not a black-and-white issue, everyone could not be placed into one of two categories, and comparisons were difficult to make. However, one person stood out among all the others with regards to her distress and cultural differences.

The individual who reported severe emotional distress was one of the minority participants. She self-reported she did have depression and anxiety after being diagnosed with cancer. She stood out from the others with regards to emotional support, economic issues, and education. She was one of few participants who felt she did not have emotional support from the people she loved. She was also the participant who reported severe financial difficulties and her furniture was repossessed after being diagnosed with cancer when she could not work. She had wanted counseling but had been unable to afford it. This participant also felt the most confused by her diagnosis and the medical jargon she encountered.

Her psychological, emotional, and financial distress was so severe that at one point she was contemplating suicide. Her saving grace came in the form of a support group. She went to a support group meeting and made friends. She was told her emotional distress was normal and that everyone in the support group was on something for their emotions and anxiety. She said the women in her support group told her it was okay to be on medications. This participant then went to her doctors and began taking psychotropic medications. She reported the medication had been helpful, and she never wanted to get that low again. She said, "I don't think I'll go back to that. I'm not going to allow that."

Two additional participants acknowledged suicidal thoughts. One had a fleeting thought for a moment about how she would die if she refused chemotherapy treatments (she did not refuse) to combat the cancer. The second participant explored

assisted suicide in Oregon as a possible future option in case the cancer ever came back with a vengeance and tried to take over.

5.7 Depression Symptoms

Participants were asked about depression symptoms after they were diagnosed with cancer, which included: a depressed mood, diminished interest in almost all activities, significant weight fluctuation, insomnia/hypersomnia, and feelings of restlessness, fatigue, feelings of worthlessness or excessive guilt, diminished ability to concentrate, and/or recurrent thoughts of death or suicide. All participants endorsed three or more depression symptoms at various times after diagnosis. The most frequently mentioned symptoms were fatigue, sleep disturbances, and weight fluctuations. The participants had their theories on this and attributed it to the following: side effects of chemotherapy treatments (most frequently mentioned), menopause, lack of hormones, hot flashes, aging, side effects of their other strenuous treatments, such as their surgeries and radiation treatments, mood, and depression. The side effects of chemotherapy were the most frequently mentioned explanation for these symptoms. Many participants reported these symptoms or side effects abated or they felt better once their chemotherapy phase was completed. For others, medications were helpful in relieving these symptoms/side effects.

In the discussions in this chapter, 11 themes have been identified and supported by the participants' narrative quotes. In addition, depression and depression symptoms have been discussed. The following chapter will discuss the results and the implications for the future.

CHAPTER 6

DISCUSSION

This qualitative study has given a voice to women in the North Texas area with gynecological cancers. Through this voice the participants were able to share their experiences, which resulted in 11 themes: *Wide Range of Emotions at Diagnosis, Advocacy, Support Groups, Personal Growth, Spirituality, Longevity, Complex Support Systems, Chemotherapy Side Effects, Highly Bonded With Doctors, Medications, and Counseling*. These themes have led to the concept of resiliency. All of the participants in this study employed a wide variety of coping mechanisms while they coped with their cancer diagnosis. I feel the women's ability to be pro-active is really due to their ability to be resilient at a time in their lives when faced with a life-altering diagnosis. In this final chapter, the results of this study will be discussed, along with the implications for future social work practice, policy, and research.

6.1 Participants

A total of 10 North Texas women participated in this study. All the women had been diagnosed with a gynecological oncology diagnosis at some point in their lives. Seven of the women had an ovarian cancer diagnosis, one had cervical cancer, one had endometrial cancer, and one had diagnosis of vaginal and cervical cancer. The participants ranged in age from 28 to 67 years of age. The demographics were similar

to the empirical literature review as this population was predominantly older, well-educated, and Caucasian.

Half of the participants expressed sexual concerns. Studies from the empirical review also found sexual problems in their samples. Meyerowitz et al., (2000) revealed almost half of their cervical cancer patients experienced a loss of sex drive, but few of their participants found this to be a bothersome side effect. Carter et al., (2005) found 67% of their cancer survivors were not satisfied with their sex lives. They cited painful sex and low libidos as their main sexual issues. Cain et al., (1983) did a study on newly diagnosed patients one month from their diagnosis and found that none of the women were having sex anymore. The two main reasons cited in that study were the women were told to abstain after surgery or they had concerns about bleeding and discharge with sex.

The two youngest participants expressed a sense of loss over infertility. This issue did not apply to the remaining eight participants who were past child-bearing age. This loss over infertility is similar to what Carter et al., (2005) found in their study as well.

Half of the participants were misdiagnosed. More participants with an ovarian cancer diagnosis were misdiagnosed, but the sample also included a large number of participants (n=7) with an ovarian cancer diagnosis as opposed to cervical, vaginal, and uterine cancer diagnoses (n=3). However, in working with the ovarian cancer population, I was taught that being misdiagnosed is not an uncommon phenomenon.

6.2 Themes

The first identified theme is a *Wide Range of Emotions at Diagnosis*. The women reported a wide variety of emotions including shock, anxiety, grief, anger, nervousness, being terrified, feeling panicked, and feeling depressed, to name a few. A cancer diagnosis is a life-altering event, and it is only normal that the women would have felt these negative emotions. The empirical literature review included two studies that addressed diagnosis reactions. Cain et al., (1983) examined the reactions of newly diagnosed gynecological oncology patients and revealed they felt shock, anxiety, and symptoms of mild depression. Wenzel et al., (2002) learned that 85% of their sample was significantly distressed upon hearing their initial cancer diagnosis. A study by Miller, Pittman, & Strong (2003) found that even six months after completing treatments, 57% of their gynecological oncology sample felt they needed help with their emotional problems. “The most common emotional concerns were feeling nervous (40% of subjects), being worried (34%), fear (25%), needing someone to talk to (24%), sadness (21%), and loss of control (17%)” (Miller et al., 2003, abstract). The literature supports this finding that women have strong negative emotional reactions at diagnosis and after cancer treatments are completed, emotional support is still needed.

The second identified theme was *Advocacy*. All the women were involved in advocacy work that included education, awareness, fundraising, and supporting their cause in a variety of ways. The empirical literature review did not include any advocacy studies. Susan Vogt Temple (2002) wrote an article on the benefits of advocacy work in the gynecological oncology arena. She wrote that not only were

patients advocating for themselves in the medical community by seeking information, exploring treatment options and future treatment ramifications, but also by determining which staff members and facilities they would be using. Patients advocate for themselves by utilizing support groups. They also become professional grassroots advocates through professional advocacy venues, such as the National Ovarian Cancer Coalition and the American Cancer Society.

A pilot study by Levin & Silver (2007) evaluated a gynecological oncology psychosocial program at a large hospital. The study revealed that, “About half of the women (51%) were interested in becoming a mentor at some point, and 43% were interested in advocacy” (p. 83). Whereas half of the participants in the Levin & Silver study aspired to become mentors and advocates, the women in this study had achieved that status. Some of the participants were already mentors to others.

The third theme is *Spirituality*. The participants shared how their spirituality has helped them cope with their diagnosis. The literature supports this theme. One of the quality of life studies from the empirical literature review (Wenzel et al., 2002, p.142) reported, “Spiritual well-being was significantly positively associated with personal growth and mental health.” Meyerowitz et al., (2000) also found after emotional support that religious faith was the second most helpful coping mechanism. A study (Lauver & Connolly-Nelson, 2007) on breast cancer and gynecological patients recently completing their oncology treatments found religion to be a primary coping mechanism for their sample, followed by acceptance and distraction.

The fourth theme is *Complex Support Systems*. The women in this study revealed they had many people in their lives with whom they could rely on for support. These individuals included family, friends, co-workers, strangers, neighbors, nurses, staff, and support group members. Even with various types of support, two participants would have liked emotional support from their loved ones. Meyerowitz et al., (2000, p.353) reported, “Although patients appear to have good support overall, most wanted additional access to cancer-related support.” A qualitative study by Ferrell, Smith, Ervin, Itano, and Melancon (2003, Abstract) revealed that social support and social well-being were the highest priority of the women in their study, “reflecting the need for support from family, friends, and other women...”

The fifth theme is *Support Groups*. All 10 participants were involved with one or more support groups. For quite a few of the women, this is where their passion for advocacy work started. Temple (2002) wrote about the support group setting and reported that, “Advocacy in this setting empowers patients and family members through education and validation of shared individual and group experience” (p.232).

At the support groups meetings, the women had the opportunity to educate and motivate one another to do advocacy work both locally and nationally. Had the participants not been involved in support groups, it is very possible the themes could have turned out quite differently. It is difficult to say, but perhaps the resilient ones join support groups and the non-resilient women do not either join a support group or perhaps do not fully understand the importance of belonging to a support group, or maybe they are at home struggling. It is possible that many women are working and

resilient and perhaps do not have time to join a support group. The women expressed how important their support group was to them because of the emotional support, mentoring, education, and friendship.

From the empirical literature review Wenzel et al., (2002) reported 12% of their sample joined a support group at the beginning of their cancer journey, while another 56% of their sample revealed they would have gone to support group meetings if it had been offered to them at the beginning.

Passik, McDonald, Dugan, Edgerton, & Roth (1997) wrote:

Support groups are usually great adjunctive intervention modality for distressed cancer patients and family members. Hospitals and community organizations often sponsor groups that are professionally run or self-help/lay led. The professionally run groups usually use educational, supportive, or cognitive-behavioral methods, while the lay groups generally focus on education, practical advice, modeling, and serving as a source of mutual support and advocacy (section 8).

The sixth theme is *Chemotherapy Side Effects*. The women in this study had a large range of chemotherapy side effects. Most of the women shared these side effects which eventually diminished or improved after the chemotherapy was completed. They reported they could see improvements in their memory and fatigue over time. For the women still receiving chemotherapy, they learned to adjust their lifestyles and daily events to accommodate the side effects. Many of them took naps to assist with the fatigue.

In the literature review, Lutgendorf et al., (2000) revealed their sample of chemotherapy patients also had a great deal of fatigue and less vigor than non-

chemotherapy treated patients. Their sample showed “significantly poorer emotional well-being, physical well-being, and functional well-being” (p.1405). This makes sense after one reads the extensive list of symptoms my participants had with their chemotherapy treatments. If one is experiencing vomiting, nausea, fatigue, impaired sleep, and numbness, it would only make sense that these women would not feel up to par emotionally and functionally as they did prior to their treatments. Cain et al., (1983) revealed their chemotherapy patients who were taking very severe chemotherapy drugs had depression and social impairment at home, and experienced increased dependency on their family members. More research needs to be done on chemotherapy side effects mimicking depression symptoms.

The seventh theme is *Longevity*. Patients in this study were concerned with thoughts of dying, length of life, and recurrences. A study by Ferrell et al., (2005) examined ovarian cancer patients’ quality of life and their study revealed, “Fears of recurrences and dying are prevalent in ovarian cancer survivors” (p. 1143). From the empirical literature review, the study by Wenzel et al., (2002) revealed that 36% of their women were fearful of getting a second cancer and 22% were fearful of having a recurrence. A study (Lauver & Connolly-Nelson, 2007) on cancer survivors who had recently completed their cancer treatments also found that their women were also concerned by thoughts of mortality.

The eighth theme is *Personal Growth*. The participants reported many good things came from their cancer experience such as emotional growth, increased positive personality characteristics, and improved interpersonal relationships. Wenzel et al.,

(2002) reported, “Our data appear to support the potential mediating effect that constructs such as spirituality or confidence-managing survivor issues can have on positive growth” (p. 151).

A qualitative study (Foley et al., 2005) on male and female cancer survivors’ revealed personal growth was one of its four themes, with women acknowledging personal growth more than men. Personal growth in that study encompassed a greater appreciation for life, cancer improving their lives, and it being a positive growth experience for them.

The ninth theme is *Bonded to Doctors*. The participants in this study expressed high regard for their doctors and felt this was a very significant relationship in their lives. The empirical literature review revealed that in the Lutgendorf et al., (2000) study, patients who used active coping mechanisms also had better relationships with their doctors. Perhaps this is due to the patients being self-motivated and using their active coping skills to seek out the best medical care possible for themselves. In the Lutgendorf et al., (2000) study, active coping mechanisms were also associated with less distress and better social well-being.

Another study (Meyerowitz et al., 2000) revealed 90% of its sample felt supported by the medical staff with regard to treatment issues and kindness. A study by Wenzel et al., (2002) of ovarian cancer survivors revealed 31% “advise health care professionals that compassion and sensitivity to issues continues to be important in addition to a positive attitude (13%)” (p. 150).

The tenth theme is *Medications*. Participants used a wide variety of medications to manage the side effects of their treatments. More than half of the women were on some type of psychotropic medication at the time of the interview. The literature review included a study by Cerfolio (1995), a psychiatrist. For her patients, she prescribed benzodiazepines for anxiety and antidepressants for depression relief. Another study (Ell et al., 2005) from the literature review reported psychotropic medications were also beneficial for pain control too:

Fourteen (12%) of the women with major depression and eleven (16%) of the women with dysthymia alone, reported currently receiving medications for depression. Five additional women who did not meet criteria for major depression or dysthymia reported antidepressant medication use at baseline. Women who reported receiving antidepressants were less likely to have major depression (47% vs 87%) and pain symptoms (47% vs 67%) and more likely to report anti-anxiety medication use (27% vs 2%) compared to depressed women not receiving antidepressants (p. 5).

In a pilot study, Evans et al., (1988) examined depression and quality of life in cancer patients and a control group. The first group received adequate anti-depressant treatment and the control group received inadequate anti-depressant treatment. The authors did not specify how inadequate treatment would be defined. Evans et al., (p. 75) reported:

The results of the present pilot study suggest that depressed cancer patients who receive adequate anti-depressant treatment demonstrate significant improvement in depression after this treatment. Although major depressed cancer patients who did not receive adequate treatment also showed improvement in depression, these untreated patients showed less improvement in depression than the treated patients and continued to have elevated depression ratings. The major depressed patients who received treatment also had a better psychosocial adjustment to their cancer (PAIS) when compared to depressed cancer patients who did not receive antidepressant treatment.

The eleventh theme is *Counseling*. Many of the participants had counseling after their diagnosis. Most sought out counselors and chaplains on their own, and some were recruited by their doctors for counseling Ph.D. studies. On an interesting note, three of the participants had counseling backgrounds. From the empirical literature review, Meyerowitz et al., (2000) reported that 57% of their participants wanted to speak with a counselor. A study by Wenzel et al., (2002) revealed 43% of their sample would like to have spoken to a counselor at the time of the study about their survivorship issues. Two additional studies from the literature review (Cain et al., 2006; Manne, et al., 2007) revealed counseling was beneficial in reducing depression and distress in both of their studies. Only one participant in the study had wanted counseling and had not yet received it due to lack of finances.

6.3 Depression

Depression or the feeling of being depressed is a difficult emotional issue to study in a retrospective self report qualitative study. As one can see with this study, the women experienced a wide variety of emotions at diagnosis, including anxiety, shock, and feeling depressed. They had each been through quite a journey with their gynecological cancer experience and at the beginning had psychological distress. They all managed to find ways to cope whether it be with the help of a loved one, emotional support from their support group members, or through personal growth to name a few.

The one person with the most depression and psychological distress was one of the minority participants. I believe if she had joined a support group earlier she

would have been in a better place emotionally throughout her oncology diagnosis journey. She benefited a great deal from the support group. It gave her emotional support, friendship, it normalized her emotional experience, it let her know it was okay to take psychotropic medications, and got her motivated to get on psychotropic medications. The support group educated her on all aspects of having cancer, and it got her involved in advocacy work. She arrived at the interview with educational materials for me on her type of cancer and then during the interview she took the opportunity to educate me on what she had been learning about her cancer diagnosis.

6.4 Depression and the *DSM-IV-TR*

The *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)* (APA, 2000) was originally created to classify mental health issues for statistical tracking purposes. Now it is considered the holy grail of the mental health field. There is no category to specifically address the issue of cancer patients and emotional distress or depression in the *DSM-IV-TR*.

All of the participants endorsed three or more symptoms of depression after receiving their diagnosis of a gynecological cancer. The most endorsed were fatigue, sleep disturbances, and weight fluctuations. The participants had their theories on this and attributed it to the following: side effects of chemotherapy treatments (most endorsed), hot flashes, menopause, lack of hormones, aging, side effects of their other strenuous treatments, such as their surgeries and radiation treatments, mood, and depression.

There was a bit of difficulty at times with obtaining depression symptoms. For instance, when one participant was asked if she had a diminished interest in all activities she reported yes, with sex. Another participant was asked if she had significant weight fluctuations and she reported no, she gained 15 pounds, she said. It is my belief that in the future, these questions would be better served if on a quantitative tool as opposed to an interview format.

As the National Cancer Institute (2006) reported earlier in this paper, chemotherapy symptoms mimic depression symptoms. The DSM-IV-TR would have us believe if someone has depression symptoms then they could very well have depression. The women in this study felt the majority of these symptoms were brought on by the chemotherapy. Of course these women would know their bodies and their chemotherapy time line well. So perhaps the chemotherapy mimicked depression symptoms or perhaps the chemotherapy gave them chemically induced depression symptoms. It is hard to say either way which would be more accurate. It is a topic that should be studied in greater detail. What is known is that the chemotherapy was very emotionally and psychologically distressing to the women in addition to being physically challenging.

My goal with this study was not to diagnose depression, as this would have been inappropriate. I did not ask the women if these symptoms all occurred in the same two week period or longer. I did not use a depression inventory to diagnose depression. My goal was to look at the participants experiences and not diagnose.

Retrospective depression turned out to be a great deal harder to study than I had previously imagined. In the future, it might be best to study depression in a medical setting where the researcher would have access to the medical staff, medical records, and diagnosing tools, so that comparisons can be more readily made.

After receiving a cancer diagnosis, only one person reported she had been diagnosed with anxiety disorder. Another person was not sure if she had been diagnosed or not with depression. The remaining eight women reported no mental health diagnosis after receiving their cancer diagnosis. Most of the women endorsed in the past after their cancer diagnosis that they felt a little depression, mild depression, some depression, moody, emotional, or had depression at times which sometimes lasted a few days, or only at night time, or for an unspecified amount of time. Six of the women were on psychotropic medications at the time of the interview. Of those four on Effexor they reported it really helped their hot flashes, mood, and sleep disturbances. As the National Cancer Institute (2004b) reported earlier in this paper, “serious depression is not experienced by everyone with cancer.”

Perhaps some minimized their depression experiences. Perhaps cancer made them stronger, and they did not have what would be considered major depression. Perhaps what I meant by depression and what they perceive as depression are really two different concepts and perceptions. More research needs to be done in this area. What is significant in this study is that no matter how the participants felt in the past, they were all pro-active in receiving help for themselves emotionally.

All of the women in the study were pro-active in that they joined support groups and became involved with advocacy work. Many received counseling and/ or began taking psychotropic medications.

Chemotherapy was a huge factor for the women. Since it appears that the chemotherapy side effects mimic depression symptoms, perhaps a new category needs to be created in the *DSM-IV-TR* to address the particular needs of oncology patients with this phenomenon. I suggest that the new category could be called Mood Adjustment to Cancer which would include chemotherapy side effects, grief, losses, fears, anxiety, depression, and depression symptoms.

Kornblith et al., (1995) examined quality of life and ovarian cancer. They found many of the women reported significant psychological distress.

The high prevalence of significant psychological distress in ovarian cancer patients suggest that a more rigorous effort is required to identify, evaluate, and treat them. The need for improved evaluation and management of psychological distress in this population is consistent with findings from studies involving various patient populations reporting that their psychiatric needs are frequently going undiagnosed and untreated: 25% of cancer patients, 46-59% of primary care patients, and 81% in the community. The undertreatment of psychiatric disorders is most likely due to a combination of factors, including patients' underreporting of emotional distress, limited clinician knowledge of assessment and therapies, both physicians' and patients' feelings of stigma attached to mental illness, and lack of affordable therapy (p. 240).

While the women in this study did report significant psychological distress at the time of their diagnosis, overall they reported a good quality of life. Even the one minority participant who experienced the greatest depression and emotional distress reported she received a great deal of help when she began attending the support group

meetings, thus decreasing her depression and distress and improving her quality of life. Few studies in the empirical literature review addressed the concerns of minority women. One study (Miller et al., 2002) reported no race differences between their African-American and Caucasian women. Two studies on Latino immigrants (Ell et al., 2005; Meyerowitz et al., 2000) reported depression, support, pain, and financial issues for their sample. Due to the limited number of existing studies more research is needed in the future to address this issue.

6.5 Resiliency

As previously stated (Masten & Reed, 2002, p. 75), resiliency is the consistent “positive adaption in the context of significant adversity or risk.” Norman (2003) describes resiliency as, “The ability to bounce back from or to successfully adapt to adverse conditions” (p. 3). She feels resiliency is a combination of 11 personality and interpersonal related factors: self-efficacy, having a realistic view of the environment, engages in problem solving, has a mission or purpose, is empathetic, uses humor, distances themselves from dysfunction, has both masculine and feminine characteristics, has positive and caring relationships, has a social network of family and friends, and has a can-do attitude with high but reachable expectations.

The women in this dissertation study certainly have self-efficacy, a sense of purpose, engage in problem solving, are realistic about their situation, and are empathetic towards others. They can be assertive with their medical care yet are expressive, social and nurturing, and they have complex support systems where caring relationships are a high priority. The study by Wenzel et al., (2002) concluded that

resiliency and personal growth are positive coping mechanisms that serve cancer survivors well with their overall quality of life. Overall, the women in this study reported good quality of life. They shared all of their wonderful activities and accomplishments with me. At the time of the interview, three participants were contemplating writing books about their lives and their gynecological oncology experiences.

The 10 women in this study are indeed resilient. They are active with their problem solving and highly motivated. The Lutgendorf et al., (2000) study reported, “Those using active coping reported better social well-being, better relationships with their doctors, and less overall distress” (p.1402). Another aspect is that having cancer may make a person stronger and more able to handle life’s stressors.

Coughlin et al., (2007) writes,

In order to provide appropriate individual and community support for cancer survivors, there is a great need to better understand how people who have survived cancer or other serious illness adapt positively to health challenges and to identify effective approaches for helping people cope with health challenges over their lifetime. Studies have identified a number of personal factors that are associated with resilience, increased quality of life, and positive adaption to illness. Of particular interest is the ability of individuals to survive or even thrive despite an adverse event, as influenced by both individual factors such as resiliency and external factors like social support. The experience of having a potentially life-threatening illness can lead to positive adaption and increased ability to thrive despite difficult circumstances. The cancer survivorship movement and the cancer community in general provide important resources for improving quality of life and alleviating human suffering and distress among patients and survivors and for adding personal meaning and hope to people’s lives (abstract).

This study has identified 11 themes that can be used as a prescription for coping for all future gynecological oncology patients. Taken together they offer a frame work to develop resiliency. I believe the following two themes normalize the emotional experiences of having a cancer diagnosis: *Wide Range of Emotions at Diagnosis* and *Longevity*. *Chemotherapy Side Effects* is something that is difficult to bear but steps can be taken to relieve the side effects. The remaining eight themes are the coping mechanisms the participants actively engaged in to help themselves through a difficult emotional journey: *Advocacy*, *Support Groups*, *Medications*, *Bonded with Doctors*, *Spirituality*, *Complex Support Systems*, *Counseling* and *Personal Growth*. The *Support Group* theme holds the key to many of these coping mechanisms as it is a pathway to other themes. There is no need to “re-invent the wheel.” If women in support groups are key informants in developing information and ways to cope with gynecological cancers, then it would behoove all newly diagnosed women to join such support groups, since they have already researched many issues and have important information to share.

6.6 Practice Implications

This study has led to many social work practice implications in the field of gynecological oncology. Social workers should use a strength-based perspective in working with cancer patients and encourage them to use all of their resources to battle their disease. The medical community should continue to hire medical social workers for their hospitals, clinics, cancer centers and private practices. These facilities should have social workers provide comprehensive psychosocial assessments targeting

patients' needs and resources on every newly diagnosed cancer patient in order to be pro-active rather than reactive. Each newly diagnosed cancer patient should receive a cancer patient planner. Cancer patient planners should include a comprehensive list of relevant phone numbers for the doctors, nurses, clinics, social workers, financial counselors, and case managers. Written resources should be included in the cancer patient planner for: (a) the specific cancer diagnosis (b) the American Cancer Society (c) Gilda's Club (4) Lance Armstrong's Livestrong Web site (5) lists of local support groups (6) access list to lawyers (pro bono for low income women) (7) if possible, the name and phone number of a local cancer survivor with the same diagnosis to answer questions about chemotherapy and to dispel the myth that support group meetings are depressing (8) a current list of oncology counselors/therapists who will take new clients (9) financial resources (10) specific diagnosis groups, such as the: National Ovarian Cancer Coalition and the National Cervical Cancer Coalition, and (11) information on how to obtain a "Chemo Angel."

Many oncology clinical social workers are trained therapists, but work full-time already in the oncology field as medical social workers. Perhaps some could be encouraged to go into private practice part-time as these social workers know the needs and stressors of having an oncology diagnosis and would be knowledgeable therapists. Evidenced-based therapies such as Cognitive Behavioral Therapy and supportive/crisis intervention psychotherapies have been found effective in helping cancer patients. In addition, oncology social workers could be encouraged to facilitate gynecological oncology support groups.

Social workers in the medical community should convey to newly diagnosed patients the importance of support groups, as this appears to be a major factor in this study that aids participants' resiliency. Newly diagnosed ovarian cancer patients should be given the book *Torch: Tales of Remarkable Courage and Hope*. At the community level, local social work schools can create a medical social work curriculum at the university level that focuses on crucial medical diagnoses, such as having cancer, its effects, pertinent resources and the best practice and evidenced-based research. Such a class would encourage social work students to take an interest in medical social work and cancer related activities, such as the American Cancer Society activities. Not only would it peak the students interest in working with cancer patients, but it would also provide crucial education for those new graduates who want to go into medical social work and propel the advocacy movement.

6.7 Policy Implications

The Ovarian Cancer National Alliance (2009) has already determined policy goals for their National Agenda, which includes to obtain at least twice the amount of funding from the federal government to expand ovarian cancer research, continue to educate women and medical providers on the symptoms of ovarian cancer and the risks, and to train advocates to work within all levels of the government's political processes. As social workers, we can lobby the federal government for more funding (for all gynecological cancers) and educate women and medical staff in our communities on gynecological cancers and its effects. We can continue our political efforts to support and endorse the advocacy movement and funding movements in our community. We

can do grassroots lobbying for more government assistance in paying for medical bills. At the time of the interviews, the study participants all had medical insurance. At some point in the future and for many others with cancer diagnoses, they may not have medical insurance and social workers need to be pro-active in state legislatures to ensure that gynecological cancer patients can obtain affordable medical insurance for their on-going evaluations, treatments, and follow-up appointments.

6.8 Research Implications

The academic and medical communities must continue to research all aspects of gynecological cancer. Continued advocacy is needed for more federal money to do research on all aspects of gynecological oncology and to find a cure.

The National Cancer Institute (2009a) keeps track of how many millions of dollars are allocated to more than 15 different types of cancers for research and clinical trials. The totals are not exact and are estimates, but based on the estimates alone, one can see a huge gap in the money awarded for gynecological cancers. In 2003, cervical, ovarian, and uterine cancers combined received approximately \$203.9 million total for research and clinical trials, while breast cancer received \$548.7 million. In 2007, cervical, ovarian, and uterine cancers combined received \$195.9 million total and breast cancer was awarded \$572.4 million. As one can see, four years later, the money allocated by the federal government towards gynecological cancers actually decreased by \$8 million and the money for breast cancer increased by \$23.7 million. According to the American Cancer Society (2009) more women were diagnosed in 2008 with breast cancer (182,460) than gynecological cancers (78,490), but the gynecological cancers

have a higher mortality rate than breast cancers: 36% for gynecological cancers versus 22% for breast cancers (percentage was configured based on figures for newly diagnosed cases and death rates for 2008). Breast cancer research and clinical trials are certainly a worthy cause, but gynecological cancers with their high mortality rates should receive more federal funds for research and clinical trials.

A few of the participants also mentioned the benefits of women getting the HPV vaccine so other women do not have to go through what they went through. This vaccine appears promising, but further research is needed to determine the longevity of the HPV's vaccine's protective benefits.

This study has added to the existing body of knowledge on gynecological cancers. Future studies would benefit from using quantitative tools, triangulation, younger women, long-term survivor studies, minorities, those without medical insurance, a larger sample size, more culturally diverse samples, equal sizes of different gynecological oncology diagnosis for comparisons, long-term studies with follow-up, and national cancer data information with random sampling. Many of the women in this study have experiences and stories that are worthy of being case studies. Future gynecological oncology research should incorporate case studies, as these participants have a great deal to share and would make impressive case studies and contributions. The 11 themes from this study should be the basis of future research. The concept of gynecological oncology and resiliency deserves special research attention as well.

While this study did not use a random sample and is not generalizable to the general gynecological oncology population in America, I feel the results are hopefully representative of the women with gynecological oncology diagnoses in North Texas.

6.9 Conclusion

This study has added to the gap in the knowledge of gynecological oncology. In addition, the insights, wisdom and information that the participants of this study have shared on how to handle a complex medical diagnosis offer a framework to study the concept of resiliency.

APPENDIX A

EMPIRICAL LITERATURE REVIEW CHART

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|---|---|--------|--|--------------------------|--------------------|---|--|
| Kornblith, Thaler, Wong, Vlamis, Lepore, Loeth, Hakes, Hoskins, & Portenoy (1995) | Quality of life | None | N=151 ovarian | Descriptive/longitudinal | Interviews Surveys | Mental Health Inventory (MHI) (depression subscale) | 17% highly depressed 17% some depression/emotional 22% highly anxious 33% high levels of psychological distress High distress = physical side effects, less physical functioning, advanced cancer, & inpatient status. |
| Nail, King, & Johnson (1986) | Coping & mood: during / after radiation | Coping | N=30 (ovarian, cervical, endometrial, & vaginal) | Descriptive/longitudinal | Interviews Surveys | Profile of Mood States (POMS) (depression subscale) | Patients were most distressed during last radiation treatment, then it decreased after treatment. Overall average level of depression was low. Problems coping with home, sleeping, hobbies, & social activities. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|--|--------|---------------------------|-----------------------------|--|-----------------------------------|--|
| Roberts, Rossetti, Cone, & Cavanagh (1992) | Quality of life post surgery (survivors) | None | N=32 gyn. N=100 breast | Descriptive/ comparative | Interviews Surveys (Qualitative) | SCL-90-R (depression subscale) | Gynecological patients had slightly more psychological distress than breast cancer patients. 25% of gynecological patients had transitory depression symptoms. Younger had more distress. 85% = satisfied with hospital social worker. Coping = busy/trying to forget cancer. Some would have liked counseling information. Overall, good quality of life. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|---|-----------------------------|--------|---|-------------------------|-------------|-------------------------------------|--|
| Miller, Pittman, Case, & McQuellon (2002) | Quality of life (survivors) | None | N=85 (cervical, uterine, & ovarian) N=42 healthy | Descriptive/comparative | Surveys | FACT-G (emotional well-being scale) | Cancer patients had slightly better emotional well-being than healthy sample. Older cancer patients had better emotional well-being than younger, but less social well-being than younger patients. Lower quality of life = ovarian, radiation, multiple treatments, less education, & less support at home. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|---------------------------------------|--------|---|--------------------------|----------------------------|--|--|
| Lutgendorf, Anderson, Rothrock, Buller, Sood, & Sorosky (2000) | Chemo patients quality of life & mood | None | N= 24 chemo (cervical, ovarian, & endometrial) N=24 non chemo (cervical & endometrial) | Descriptive/ comparative | Surveys Medical records | Profile of Mood States (POMS) (subscale) | Chemotherapy patients had poorer emotional well-being and more depression than non chemotherapy patients. Chemotherapy = more fatigue, less vigor, and more physical problems. Avoidant coping = more depression & anxiety. Active coping = less distress & better social/ relationships. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|--|-----------------|-------------------------------------|-------------|-----------------------|---|---|
| McCorkle, Tang, Greenwald, Halcombe, & Lavery (2006) | Depressive symptoms (survivors) | Quality of life | N = 208 cervical | Descriptive | Surveys Interviews | Centers for Epidemiologic Studies - Depression (CES-D) | 21.3% depression symptoms: 1) increased pain 2) post radiation diarrhea 3) decreased physical function 4) increased side effects 5) changes = marriage/work 6) income < \$60,000 |
| Carter, Rowland, Chi, Brown, Abu-Rustum, Castiel, & Barakat (2005) | Infertility due to cancer treatments (cancer free: 12-45 months after treatment) | None | N=20 (cervical, ovarian, & uterine) | Descriptive | Surveys (Qualitative) | Centers for Epidemiologic Studies-Depression (CES-D) & Impact of Event Scale (distress) | 40% depression 35% mod/severe depressed 50% still grief stricken by infertility Grief (Qualitative): 1) adjustment & acceptance 2) survival (beat cancer/ happy to live) 3) negative feelings (grief, sadness & anger). Sexual difficulties. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|---------------------------------------|---|--------|--|-------------|-------------|--|--|
| Parker, Baile, DeMoor, & Cohen (2003) | Quality of life & psycho-social factors | None | N = 351 (17% gyn., 30% breast, 31% gastro-intestinal, & 22% urologic) | Descriptive | Surveys | Centers for Epidemiologic Studies-Depression (CES-D) | 32% depressed Singles = more depressed Older/married/social support= less depressed Older = less anxiety/good support |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|---|---|--------|--|--------------------------|---------------------------|---|--|
| Norton, Manne, Rubin, Hernandez, Carlson, Bergman, & Rosenblum (2005) | Distress, support, & control (advanced ovarian cancer) | None | N= 143 ovarian | Explanatory (SEM) | Survey | Mental Health Inventory (MHI) (psychological distress) | a) low support associated with low self-esteem which was associated with more psychological distress b) more physical problems associated with less control and more psychological distress |
| Bradley, Rose, Lutgendorf, Costanzo, & Anderson (2006) | Mental health & quality of life (cancer free: 5-20 years) | None | N= 152 (cervical & endometrial) N= 89 healthy | Descriptive /comparative | Survey Medical records | Centers for Epidemiological Studies- Depression (CES-D) & Profile of Moods State (POMS) | 27.6 % depressed (cervical) 21.4 % depressed (endometrial) 17% depressed (healthy) Cervical = more anxiety, more anger, & more confusion Less depression = working |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|------------------------------------|----------------------------------|--------|----------------|-------------|--|----------|--|
| Meyerowitz, Formenti, & Ell (2000) | Depression & radiation (Latinos) | None | N= 50 cervical | Descriptive | Interviews Surveys (Qualitative) | CES-D | 63% = depression Qualitative: Helpful = 1) emotional support (28%) 2) religious faith (14%) 90% = supportive staff 84% = knew correct diagnosis 86% = felt they would be cured Group was split on the information issue. Depression = social support, stress, physical problems, & economic issues. Talk to counselor or survivor = would have liked this option. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|-------------------------|--|---|-----------------------------|-------------------------------------|---------------------------------|---|
| Manne, Edelson, Bergman, Carlson, Rubin, Rosenblum, Hernandez, Rocereto, & Winkel (2007) | Counseling intervention | Cognitive affective - social processing & Moderators of change | N= 353 (ovarian, endometrial, peritoneal, cervical, vaginal, vulvar, uterine, & fallopian tube) | Experimental / longitudinal | Interviews Surveys Counseling | Beck Depression Inventory (BDI) | Entire sample had mild to severe depression symptoms 35.8% minimal 39% mild/mod 21.3% moderate/severe 4% severe Depression symptoms declined after counseling intervention. More depression symptoms = younger, more physical problems, & less expression of positive emotions. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|---|-------------------------|--------|---|----------------------------|-------------------------------------|---|--|
| Cain, Kohorn, Quinlan, Latimer, & Schwartz (2006) | Counseling Intervention | None | N= 80 (endometrial, cervical, ovarian, vulvar, & other) | Experimental/ longitudinal | Interviews Surveys Counseling | Hamilton Depression Rating Scale & Hamilton Anxiety Scale | All three groups had mild/moderate depression and anxiety at first. Depression and anxiety declined at the end of the study. Six-months later the two counseling groups had less depression and anxiety compared to the control group. Better social and less sexual problems too. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|--|--------|--|-------------|-----------------------|----------|---|
| Ell, Sanchez, Vourlekis, Lee, Dwight-Johnson, Lagomasino, Muderspach, & Russell (2005) | Depression (low income) (79% = Latina) | None | N= 472 222= gyn. (cervical, uterine, ovarian, & other) 250= breast | Descriptive | Interviews Surveys | PHQ-9 | Gynecological = 222 17% depressed (gyn.) Depressed = very few on RX, seeing a counselor, or in a support group. More depressed = younger, more physical problems, & less support RX = less depression |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|--|--------|---------------|-------------|-------------|---|--|
| Bodurka-Bervers, Basin-Engquist, Carmack, Fitzgerald, Wolf, de Moor, & Gershenson (2000) | Depression, anxiety, & quality of life | None | N=246 ovarian | Descriptive | Surveys | Centers for Epidemiologic Studies-Depression (CES-D) & Spielberger State Trait Anxiety Inventory (subscale) | 21% depression 29% anxiety Younger = more depression and lower quality of life. More physical problems associated with: 1) more depression 2) more anxiety 3) less quality of life. Lower quality of life = patients currently undergoing treatments (versus follow-up appointments only) |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|---|--------|--------------|-------------|--|---|---|
| Wenzel, Donnelly, Fowler, Habbal, Taylor, Aziz, & Cella (2002) | Quality of life (cancer free 5 + years) | None | N=49 ovarian | Descriptive | Interviews Surveys (Qualitative) | Centers for Epidemiologic Studies- Depression (CES-D) | 6% depression Survivorship distress: (Qualitative) 85% = receiving diagnosis 36% = getting a 2 nd cancer 22% = recurrence 30% = future testing Sexual difficulties 56% = would join support group 43% = wanted counseling 56% problematic = physical Overall, good quality of life |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|-----------------|---|--------|--|--------------------------|--|-----------|--|
| Cerfolio (1995) | Psychiatric evaluation by psychiatric liaison | None | N=82 (ovarian, cervical, endometrial, benign, & other) | Descriptive/longitudinal | Interviews Medical records Staff input | DSM-III-R | 13% major depression 53% adjustment disorder 32% adjustment w/depressed mood 12% adjustment w/mixed features 9% adjustment w/anxiety Referrals to psychiatric liaison for: 1) coping problems 2) depression 3) social difficulties |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|---|---|--------|--|-------------|----------------------------|--|---|
| Evans, McCartney, Nemeroff, Raft, Quade, Golden, Haggerty, Holmes, Simon, Droba, Mason, & Fowler (1986) | Depression & neuro-endocrine testing (newly diagnosed & hospitalized) | None | N= 83 (cervical, endometrial, & vaginal) | Descriptive | DSM-III Interviews Surveys | Hamilton Depression Rating Scale & Carroll Rating Scale for Depression | 23% major depression 24% nonmajor depression |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|--|---|--------|---|-------------|-------------------------------|--|---|
| Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi (2001) | Psychological distress & newly diagnosed | None | N=4496 (4.8% = gyn.) (53% = breast, lung, & colon) | Descriptive | Surveys Medical records | Brief Symptom Inventory (BSI) (subscale) | 29.6% gyn. = distressed More distress was associated with being younger than 30 years old, older than 80 years old, & single. Less distress was associated with being married. |

Empirical Literature Review Chart

| Authors | Purpose | Theory | Sample Size | Design | Methodology | Measures | Results |
|---|--|--------|---|-------------|-----------------------|---|---|
| Cain, Kohorn, Quinlan, Schwartz, Latimer, & Rogers (1983) | Psychosocial reactions = diagnosis (newly diagnosed) | None | N= 60 (endometrial, cervical, ovarian, vulvar, & other) | Descriptive | Interviews Surveys | Hamilton Depression Rating Scale, CES-D, & Hamilton Anxiety Scale | 60% mildly depressed 33% moderately depressed 3% severely depressed Mild to moderate anxiety More depression = ovarian, high grade tumors, & combination chemotherapy drugs. Initial diagnosis reaction was shock & anxiety. |

APPENDIX B

TABLE 5.3 DEMOGRAPHICS & GYNECOLOGICAL ONCOLOGY TABLE

Table 5.3 Demographics and Gynecological Oncology Table

| Age | Race | Type of Cancer | Age at Diagnosis | Staged | Surg | Chemo | Rad |
|-----|-----------------------------|---|---|--|------|-------|-----|
| 28 | Asian | Cervical | 27 | Stage 3B (Initially staged as 2A) | Yes | Yes | Yes |
| 32 | Caucasian | Endometrial | 31 | Stage 3A | Yes | Yes | Yes |
| 47 | Caucasian | Ovarian & Pancreatic | 46 | Stage 1C = Ovarian Pancreatic = Not staged (early stage) | Yes | Yes | No |
| 49 | Caucasian | Ovarian | 46 | Stage 4 | Yes | Yes | No |
| 49 | Caucasian | Ovarian | 47 | Stage 2C | Yes | Yes | No |
| 50 | Hispanic | Ovarian | 49 | Stage 3C | Yes | Yes | No |
| 52 | Caucasian & American Indian | 1. Cervical 2. Vaginal & Cervical 3. Lung | 24 = Cervical 49 = Vaginal & Cervical 51 = Lung | Cervical = Not staged (early stage) Vaginal/Cervical = Believes it was Stage 3 Lung cancer = Unsure if it is a new cancer or if the vaginal and cervical cancer spread | Yes | Yes | Yes |
| 58 | Caucasian | Ovarian | 51 | Stage 3C | Yes | Yes | No |
| 63 | Caucasian | Ovarian | 57 | Stage 3C | Yes | Yes | No |
| 67 | Caucasian | Ovarian | 62 | Not Staged (Cancer was considered late stage) | No | Yes | No |

APPENDIX C

DEMOGRAPHICS QUESTIONNAIRE

#_____

Demographics

1. What is your age?_____

2. What is your race/ethnicity?

- a) African-American or Black
- b) American-Indian
- c) Asian or Pacific Islander
- d) Hispanic or Latino
- e) White or Caucasian
- f) Other (Please write your race/ethnicity)_____

3. What was the last grade you completed in school?

4. What county do you reside in Texas?

5. What is your source of income?

6. What is your annual household income?

7. What is your health insurance status?

8. What is your current marital status?

- a) Single
- b) Married or living with partner/significant other
- c) Divorced
- d) Widowed
- e) Separated

9. Who lives with you at home?

10. Are you a caretaker for anyone?

11. How many children do you have?

12. If you have children, what are their ages and where do they live?

APPENDIX D

GYNECOLOGICAL ONCOLOGY QUESTIONNAIRE

Gynecological Cancer Diagnosis

1. What type of gynecological cancer do you have now or what type did you have in the past?

- a) Cervical (cervix)
- b) Ovarian (ovary)
- c) Vaginal (vagina)
- d) Vulvar (vulva)
- e) Endometrial/uterine (endometrium/uterus)
- f) Peritoneal
- g) Gestational Trophoblastic Neoplasm
- h) Other _____

2. What stage was your cancer in?

- a) Stage 1
- b) Stage 2
- c) Stage 3
- d) Stage 4
- e) I don't know
- f) Other _____

3. How old were you when you were diagnosed with a gynecological cancer?

4. With your gynecological oncology diagnosis, what type of treatments did you receive?

- a) Surgery
- b) Chemotherapy
- c) Radiation

d) Other _____

5. Have you had cancer before or after the gynecological cancer diagnosis? If yes, please explain what type of cancer it was and when you were diagnosed.

APPENDIX E

MENTAL HEALTH HISTORY QUESTIONNAIRE

Mental Health

1. Have you ever been formally diagnosed with any of the following?

- a) Major depression
- b) Bipolar disorder
- c) Anxiety disorder
- d) Generalized anxiety disorder
- e) Alcohol abuse or dependence
- f) Drug abuse or dependence
- g) Schizophrenia

APPENDIX F

SEMI-STRUCTURED INTERVIEW QUESTIONS

Semi-Structured Interview Questions

Pre-diagnosis

Prior to diagnosis, what was your affiliation/spiritual background?
Who were you living with?
What was your relationship like with spouse or significant other?
Describe who you relied on for support. (Family, friends?)
What was your activity level like that time? (Social, physical activity?)
What type of work did you do in or out of the home?
Were you the main caregiver for anyone in your family?
What if any major illnesses did you have prior to diagnosis?
Describe your life prior to being diagnosed with cancer.
Describe what made you happy.
Describe what caused you stress.
Describe any fears or anxiety you had about the symptoms prior to being diagnosed
What did your family friends say about the symptoms?
At what point did you go to the doctor?
What tests were done to diagnose you? How long did it take to receive a diagnosis?
Looking back, what could have helped you prior to diagnosis?

Diagnosis

How old were you?
Describe the experience of being told about your diagnosis. Via phone or office?
Alone or with a friend? What was your reaction?
What did the doctor or nurse tell you about your cancer?
What did the doctor/nurse say or do that was helpful?
What did they not do for you or what could they have done better?
What type of resources did you receive from the staff? (Written, support groups?)
How did you feel emotionally at this time?
What did you do afterwards? Where did you go?
What person or persons helped you after your diagnosis?
What was the next step in your treatment?

Post-diagnosis

What was your experience with any surgeries? Side-effects?
What was your experience for any chemotherapy? Side-effects?
What was your experience for any radiation? Side-effects?
How long did your treatments last?
For how long did you need to be followed up by the oncologist or ob/gyn afterwards?
What was your relationship like with the doctors and nurses?

How were your social relationship affected?
How was your daily life affected?
Describe any sense of loss that dealing with the cancer gave you
Describe any sense of hope that the cancer has given you.
What gave you comfort?
Describe how you coped? (Family, friends, church?)
Describe any depression or sadness you might have felt? (List of depression symptoms:
Depressed mood, diminished interest in almost all activities, significant weight
fluctuations, insomnia/hypersomnia, feelings of restlessness, fatigue, feelings of
worthlessness or excessive guilt, diminished ability to concentrate, and/or recurrent
thoughts of death or suicide)
What made it worse?
What made it better?
If you had depression, when did you realize it? (Diagnosed?)
What did your family/friends say about the depression?
If the medical staff was aware, what did they say about the depression?
What advice did your family/friends give you to get through your cancer?
What advice did your medical team give you to get through your cancer?
Describe your stay at the hospital
Describe how you were affected (Family, self-esteem, emotionally, spiritually,
physically, sexually, socially, financially, future plans?)
Describe any work or income issues you were having
Describe your experience with your medical bills and insurance company
What was the worst thing about having cancer?
Describe anything good that happened that you relate to having cancer?
Is there anything that you would like to add at this time?

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