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Distress in Women with Ovarian Cancer

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

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## Abstract

### DISTRESS IN WOMEN WITH OVARIAN CANCER

By Judith DellaRipa, PhD

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2014

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Clinicians and researchers know that women experience distress related to the diagnosis of and treatment for ovarian cancer. A review of the literature revealed that while there is interest in the topic, distress is inconsistently defined and measured. Women have been reported to have a variety of distress experiences including the challenges of late diagnosis and the treatment regimen, communication difficulties with healthcare providers, and concern about the effect of their diagnosis on their loved ones. Without information directly from women, assumptions predominate about what the experience is like and what they would find helpful from support persons. Women's perceptions about distress was identified as a gap in the knowledge leading to the present study which asked "What do women with ovarian cancer want their spouse/significant other, family, friends, and healthcare providers to know about their experience of distress during diagnosis and treatment?" A qualitative method, Grounded Theory as outlined by Glaser and Strauss in 1967 was chosen to guide this IRB approved study. Twelve women participated in audiotaped interviews contributing data for analysis using the constant comparative method. Six common themes or subcategories emerged across all the interviews and

resulted in a conceptualization of the experience as an “existential assault.” Though individual experience differed, abstraction and conceptualization of the data revealed the common themes as (a) “out of the blue like lightning”; (b) “no stone left unturned”; (c) “knowing what I don’t want to know and not knowing what I want to know”; (d) “watching you, watching me- we are both afraid”; (e) “talking yet not talking, about death”; and (f) “now I have to take care of me.” Participants expressed the need for professional support people who contribute their efforts to cure, but who also listen to the participant’s need to manage and control their own experience and to live in ways that give their life meaning and purpose. The experience of distress for the participants was intensified by the needs of those in their social network (spouse/significant other, family, friends, and healthcare providers) who also experienced distress, at times requiring participants to provide support for those who would be expected to be providing support.

## CHAPTER ONE INTRODUCTION

Ovarian cancer accounts for only 5% of all cancer in women but is the fifth leading cause of cancer-related death among women in the United States (American Cancer Society [ACS], 2014). According to the ACS, in 2014 an estimated 21,980 new cases of ovarian cancer may be diagnosed in the United States and 14,270 women may die from the disease. Ovarian cancer is staged according to the progression of disease at the time of diagnosis and graded according to the tumor pathology (National Comprehensive Cancer Network (NCCN), 2014). The stages have been defined by the International Federation of Gynecology and Obstetrics (FIGO) and recently updated (Prat, 2014). Stage I, with the best prognosis occurs when the tumor is confined to the ovaries, and surgical intervention may be an effective treatment. The five year relative survival is 92% per 100,000 women (Howlader et al., 2013). Stage II involves a tumor of one or both ovaries and includes some progression of the tumor outside of the ovaries, but is still contained within the pelvic region. Most diagnoses are Stage III disease (NCCN, 2014), which includes one or both ovaries, and confirmed metastasis to regional lymph nodes. Systemic treatment, or chemotherapy, is required in addition to the removal of the ovaries. Stage IV ovarian cancer diagnosis occurs when there is metastasis to distant lymph nodes and organs and carries the worst prognosis. The five year relative survival rate is 27% (Howlader et al., 2013). Persistent disease does not respond to treatment. When treatment is successful, there may be periods of remission, but monitoring for recurrence is always necessary.

Risk factors for ovarian cancer include age. Mostly a disease of older women, only 1.3% of women are diagnosed under the age of 20 years, with most diagnosed after the age of 45 years and more than half (69%) of women diagnosed at  $\geq 55$  years of age (Howlader et al., 2013). Other risk factors include: (a) family history of ovarian cancer, breast cancer, or colorectal cancer, and a personal history of breast cancer; (b) obesity with body mass index of thirty or greater; (c) reproductive history, with women who have given birth at term and those who have breastfed having a lower risk; and (d) medications such as hormone therapy (ACS, 2014). White women have the highest incidence of 13.3 new cases of ovarian cancer each year per 100,000 women. Asian/Pacific Islanders have the lowest number of new cases per 100,000 women per year at 9.4, and the incidence rate for all races is 12.5 per 100,000 women (Howlader et al., 2013). Although survival rates for women with ovarian cancer vary according to the woman's age and the stage of cancer progression at the time of diagnosis, the relative five year survival rate for all stages of ovarian cancer is 44% (Howlader et al., 2013). Late diagnosis, when the disease has metastasized, contributes to the high mortality rate.

## **Ovarian Cancer Diagnosis and Treatment**

### **Diagnosis.**

Diagnosis for ovarian cancer is complicated and often delayed because the ovaries are internal organs and the initial symptoms are attributed to non-specific physical and emotional conditions such as fatigue, gastrointestinal and genitourinary alterations, menstrual irregularities, depression, and stress (Goff, Mandel, Muntz, & Melancon, 2000). Ovarian cancer is sometimes called the *silent killer* because symptoms are difficult to diagnosis until after the cancer has progressed to an advanced stage (McCorkle, Pasacreta, & Tang, 2003). The notion that ovarian

cancer is a silent killer has been challenged with results from a survey of women ( $N=1,725$ ) in which the authors found that women *do* have early symptoms (Goff et al., 2000). However, Lockwood-Rayermann, Donovan, Rambo, and Kuo (2009) found that women's awareness of risk factors and symptoms for ovarian cancer was low. They reported that, among their study sample of 1,211 women with ovarian cancer, only 15% expressed familiarity with symptoms, compared to 59% with little or no familiarity of the symptoms. In a study in which researchers examined whether or not identifying symptoms early would improve prognosis, Rossing, Wicklund, Cushing-Haugen, and Weiss (2010) found that only one in 100 women in the general population would be identified as having ovarian cancer on the basis of early symptoms. Faced with a poor prognosis related to a late diagnosis, as well as the discomfort of surgical and chemotherapy treatments, many women with ovarian cancer are at high risk for experiencing psychological and physiological distress.

### **Treatment.**

According to the 2014 Clinical Practice Guidelines from the National Comprehensive Cancer Network, ovarian cancer can include benign tumors that never grow beyond the ovaries or malignant tumors that metastasize to other organs, thus becoming non-local. Early diagnosis is important for survival; however, only 15% of women are diagnosed at an early stage when ovarian cancer is most responsive to treatment, whereas 61% are diagnosed when the cancer has spread beyond the ovaries and is not limited to pelvic organs (ACS, 2014). The primary treatment for ovarian cancer is surgical staging with a total abdominal hysterectomy bilateral salpingo-oophorectomy, followed by chemotherapy (NCCN, 2014). The plan of care is individualized to preserve fertility if discovered at an early stage and if future childbearing is



desired. The disease trajectory of non-localized ovarian cancer includes increased symptom experience and pain as the tumor enlarges and metastasis occurs.

In an ethnographic review of correspondence among women diagnosed with ovarian cancer, ( $N=21,806$ ,  $n=677$  physical well-being comments) researchers reported that women expressed post diagnostic concerns related to their symptoms, including pain, fatigue, constipation/diarrhea, nausea, menstrual changes, and infertility (Ferrell, Smith, Cullinane, & Melancon, 2003a). Treatment for ovarian cancer patients may include the following procedures: surgery, to remove the ovaries and affected tissue; hormone therapy; chemotherapy, which is toxic to cancer cells as well as to normal cells; and, at times, radiation, to eradicate cancerous cells (NCCN, 2014). Further findings in the ethnographic study by Ferrell et al. (2003a) indicated that side effects of ovarian cancer treatment regimens included pain or neuropathy, fatigue, gastrointestinal disturbances, and surgical menopause. In a systematic literature review ( $N=18$ ), Arden-Close, Gidron and Moss-Morris (2008) concluded that emotional distress was a part of the experience for many women who are diagnosed with and treated for ovarian cancer, especially younger women and women diagnosed at a late stage. Thus, diagnosis of ovarian cancer remains a challenging issue, often leading to receiving treatment at a late stage (stage III, or IV), thus contributing to a poor prognosis and higher risk for increased levels of distress in women diagnosed with, and treated for, ovarian cancer.

### **Cancer-Related Distress**

Although acknowledged as a common experience among many individuals with cancer, distress is a complex, multifactorial experience and is inconsistently defined, measured, and operationalized in the literature. For example, Norton et al. (2004) defined cancer-specific

distress as “intrusive and avoidant thoughts” (p. 920). In a concept analysis of spiritual distress among cancer patients, Villagomez (2005) defined distress from the original Latin as “causing misery, pain or suffering” (p. 287). The NCCN (2013) Distress Management Guidelines provide a bit more structure and focus to the definition of distress for the *overall* cancer population:

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment.

Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (p. Dis-2)

### **Distress in Women with Ovarian Cancer**

Research findings have demonstrated that many women with ovarian cancer experience high levels of distress. Using the Distress Thermometer (DT), a self-report tool that provides a numeric rating for distress similar to the 0-10 pain scale, with the higher number indicating more distress, Johnson, Gold and Wyche (2010) examined distress in a sample of 143 women with gynecologic cancer, which included 78 women with ovarian cancer. For this population, 57% of the women measured distress levels  $\geq 4$ , which the authors determined high enough to benefit from additional assessment and referral. Studies have also indicated that women with ovarian cancer experience distress in a multitude of ways throughout the stages of disease progression and associated treatment. In addition to anxiety, depression, and diminished quality of life, women with ovarian cancer, when writing about distress, have described numerous other concerns, such as physical symptoms, side effects, and family-related worries.

In an ethnographic review of correspondence among women with ovarian cancer ( $N=21,806$ ,  $n=1282$  comments reflected psychological well-being), Ferrell, Smith, Cullinane, and Melancon (2003b) noted that psychological well-being and quality of life were thematically categorized into four broad areas, i.e., physical, psychological, social, and spiritual well-being. These four broad categories are useful for examining the concept of distress. Ferrell, Cullinane, Ervin, Melancon, Uman, and Juarez (2005) recruited participants from the mailing list of an ovarian cancer newsletter ( $N=1383$ ). Participants completed the City of Hope Quality of Life-Ovarian Cancer Tool (QOL-OVCA; Ferrell, Dow, & Grant, 1995). The investigators reported that the most common, specific concerns representing distress were treatment and fear of cancer recurrence, potentially running out of drugs or other options for treatment, suffering severe pain or neuropathy, facing changes in finances or employment, leaving husband or family alone, and confronting death and dying.

### **Women's differing perceptions.**

An additional factor of potential distress among women with ovarian cancer is that the individual woman's needs and perceptions are sometimes different from their healthcare professional's view of the woman's needs and perceptions. In an ethnographic study, Ferrell et al. (2003a) reported that women with ovarian cancer ( $N=21,806$  newsletter contributions,  $n=1282$  comments about psychological well-being) revealed that they did not feel listened to when they mentioned distressing symptoms, expressing frustration that this contributed to a delay in their diagnosis of ovarian cancer. Similarly, researchers in Canada used one-hour semi-structured audio-taped telephone interviews with 18 women with ovarian cancer, which yielded four different research reports (Fitch, Deane & Howell, 2003; Fitch, Deane, Howell, & Gray, 2002;

Howell, Fitch, & Deane 2003a, 2003b). These researchers collaboratively analyzed verbatim transcriptions of the telephone interviews and worked together to create coding strategies and categories. Many of the themes represented distressful experiences.

### **Communication challenges.**

In their analysis of the categories generated by the telephone interviews conducted with women with ovarian cancer, Fitch et al. (2002), reported that communication was a problem in the diagnostic process when the women sometimes felt that their concerns were dismissed. In the same study, the author's found that some women appreciated being given the diagnosis in incremental stages, whereas others did not want information withheld from them at any point nor given to family members prior to the patient first being told. Thus the reports from this research provided a variety of insights into the participant's experience with healthcare professionals.

Distress in women with ovarian cancer can also be affected by the level of trust they have with their healthcare providers. Dawson (1993) found that ovarian cancer patients ( $N=20$ ) preferred being told the truth about their prognosis. Although the women in Dawson's study reported needing optimistic hope, they also needed to trust their healthcare provider. One participant stated, "I was told no lies.... They didn't try to pull the wool over my eyes" (p. 43). Ziebland, Evans, and McPherson (2006) interviewed 43 women to investigate the option of choice in women's treatment for ovarian cancer. Although some women actively trusted their doctor, others expressed that there was no "real choice" (p. 363) because they were facing immediate decisions for survival and did not always have the resources to ask questions and make informed decisions. Similarly, Elit et al. (2003) conducted a study with 21 women with ovarian cancer and found that the women did not perceive that they had been given a choice of

treatment options, although they also expressed being overwhelmed and in the middle of grief at the time.

These findings suggest a critical need for health professionals to clearly understand the experience and expressions of distress in women diagnosed with and treated for ovarian cancer. As reported in the literature, distress in women with ovarian cancer was experienced in a myriad of ways; moreover, a variety of distress-related terminology was inconsistently used, making it difficult to clearly identify and address distress symptoms in women with ovarian cancer. Additional research is needed to investigate the experience of distress in this population.

### **Summary**

Diagnosing ovarian cancer is difficult because symptoms may appear late and are often attributed, initially, to other pathology, which may result in a delayed diagnosis. An advanced stage of cancer with poor prognosis, combined with cancer treatment and treatment sequelae contribute to the distress women with ovarian cancer may experience. Although it is widely acknowledged that distress is a common experience among women with ovarian cancer, the condition is inconsistently defined throughout the literature. The lack of a clear understanding of specific cancer-related distress hampers the development of effective interventions to relieve or reduce distress among women with ovarian cancer. Although numerous studies have examined the subject of distress in women with ovarian cancer, it is difficult to draw definitive conclusions from these studies' findings because of the lack of consensus or clarity regarding the definition and operationalization of the term *distress*. Because it is unknown within the healthcare profession how women with ovarian cancer perceive their own diagnosis and treatment and how they want to be supported throughout the process, asking the women themselves has the potential

to contribute clinically significant information for enhanced nursing care for this patient population.

### **Study Purpose**

Therefore, the purpose of this study was to explore the research question: “What do women with ovarian cancer want others (spouse/significant other, family, friends, and healthcare providers) to know about their experience of distress during diagnosis and treatment?”

### **Study Significance**

This study has the potential to make a significant contribution to the literature in the areas of symptom management in oncology nursing research. Numerous study findings have indicated that reducing distress in cancer patients was beneficial and improved the patients’ overall psychological, psychosocial, and physical health. A 2008 report from The Institute of Medicine (IOM) denoted many psychosocial benefits of decreasing cancer patients’ experience of distress, including the relief of needless suffering, facilitating adherence to treatment, and improvement to overall health (IOM, 2008). The Oncology Nursing Society’s (ONS, 2014) official position on psychosocial care for patients with cancer guides oncology nurses to recognize that unresolved psychosocial problems negatively influence quality of life, impacting the patient’s ability to cope, endure treatment and recover. In brief, the NCCN (2014), ONS (2009), and the IOM (2008) have each offered position statements regarding the importance of addressing psychosocial needs of patients, including distress.

Grounded theory provided the opportunity to identify significant concepts based on data provided by study participants. The purpose for using a modified grounded theory methodology was to discover whether a substantive theory would emerge that had the potential to further

nursing science. Study findings may help healthcare professionals understand the post-diagnostic experience of women diagnosed with and treated for ovarian cancer and therefore contribute to future research and nursing interventions related to the cancer-related distress experienced by women diagnosed with and treated for ovarian cancer.

## CHAPTER TWO LITERATURE REVIEW

A review of the literature demonstrated that healthcare professionals have been concerned about the experience of distress in women diagnosed with and treated for ovarian cancer. Although a definition of distress has been infrequently included in research reports, distress is most often assumed to be a psychological experience and measured with psychological instruments. In the general cancer population, Vodermaier, Linden, and Siu (2009) examined screening instruments for emotional distress. They found 106 validation studies for 33 screening measures and concluded that there was not enough data to use the tools for predicting which patients would require treatment for distress, though many of the instruments were effective for screening purposes. These authors defined distress, in the general cancer population, as “a state of negative affect that is suggestive of affective disorders” (p. 1465). Zabora, Brintzenhofesoc, Curbow, Hooker, and Piantadosi (2001) examined the prevalence of psychological distress by cancer site ( $N = 4,496$ ) and noted the following measures were used frequently in regards to distress: (1) the Profile of Mood States (POMS; McNair, Lorr, Droppleman, 1971), (2) the Psychosocial Adjustment to Illness Scale (PAIS; Derogatis, 1986), (3) the Brief Symptom Inventory (BSI; Derogatis, 1993), (4) the Symptom Checklist 90–R (SCL-90-R; Derogatis, 1977), (5) the State Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lusherne, Vagg & Jacobs, 1983), (6) the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), and (7) the Beck Depression Inventory (BDI; Beck, Steer & Brown, 1996).



Kirkova et al. (2006) reviewed 21 cancer symptom assessment instruments, acknowledging that “symptoms influence patient distress, quality of life (QOL), and survival” (p. 1459). Thirteen instruments were reported to measure distress, with researchers using a variety of terms and means for scoring. Seventeen of the instruments relied on self-assessment and 18 measured both psychological and physical symptoms. Interest in the prevalence of distress and the potential for predicting which women may suffer with distress was noted by several researchers. Manne et al. (2008) conducted a study to identify demographic, medical, and predisposing factors as well as cognitive and social processes to predict the course of psychological distress among women diagnosed with gynecological cancers ( $N = 113$ , including 91 with ovarian cancer). The researchers reported poorer adaptation among participants who were Caucasian without supportive family and friends, and who had decreased functional ability (both self-rated and physician-rated), a history of previous psychological treatment, and a more negative outlook. Interested in examining predictors of adjustment and growth, Ponto, Ellington, Mellon, and Beck (2010) used an online or a paper survey of women with recurrent ovarian cancer ( $N=60$ ) recruited from national cancer advocacy groups. They reported that younger women and those with shorter-term significant relationships were more likely to have poorer adjustment and higher levels of distress in women with recurrent ovarian cancer ( $N = 60$ ). Price et al. (2010) also investigated the prevalence and predictors of distress-related symptoms in a study that examined anxiety and depression in women with invasive ovarian cancer ( $N = 798$ ) and in their caregivers ( $N = 101$ ). This Australian study was part of the Australian Ovarian Cancer Study (AOCS). The researchers found that elevated levels of depression were apparent not only in the women with cancer but also in the women’s caregivers.

In the literature specific to women with ovarian cancer, the psychological focus for distress was evident; however, investigators have also discussed psychosocial, spiritual and physiological experiences of distress. Qualitative studies have looked at questions that confirm that distress was an aspect of the experience for many women diagnosed with and treated for ovarian cancer. With the inconsistency in definitions and measures, a modified grounded theory study to discover and report what women want others (spouse/significant other, family, friends, and healthcare providers) to know about their experience of distress during the diagnosis of and treatment for ovarian cancer has the potential to help improve the understanding of the experience of distress for this population. With this information, healthcare professionals may be able to clarify such an experience in order to research and develop effective interventions that address distress-related concerns among women with ovarian cancer.

### **Literature Review**

Using the key words “ovarian cancer,” “distress,” “gynecological cancer,” “gynecological distress,” “neoplasm,” “emotional distress,” “psychological distress,” “anxiety,” “depression,” and “worry,” an initial search was conducted using the databases, *Cumulative Index to Nursing and Allied Health Literature (CINAHL)*, *EBSCOhost*, *MEDLINE/PubMed*, and *PsycINFO*. Reference lists were reviewed for additional articles, providing further examination of the literature. Both qualitative and quantitative research designs were included as part of the selection criteria. Dissertations were excluded.

Articles that examined distress more generally in cancer or gynecologic malignancies were considered relevant. Studies that focused on genetic testing and heredity (Geirdal & Dahl, 2008) or preventive prophylaxis (Bresser et al., 2007; Fang et al., 2009) were excluded because

they did not fit the focus of this literature review, which was to examine the experience of cancer diagnosis and treatment for women. Reflecting grounded theory methodology, it was necessary to bracket the literature review information during data collection and analysis in order to minimize investigator bias and allow the theory to emerge from the substantive data. Following completion of data analysis, a final literature review was conducted to identify recent publications and to review the findings within the context of the existing body of knowledge.

### **Definitions of Distress**

Complicating the discussion of distress in women with ovarian cancer is the finding that definitions of distress are rarely provided in the literature. The NCCN (2013) definition of distress is the most comprehensive but not the most frequently used definition of distress. Extremes of distress from normal sadness to psychological pathology have been identified as an “unpleasant emotional experience” (NCCN, 2013, p. DIS-2). Psychological, social, and spiritual aspects of distress that may impact an individual’s coping abilities are outlined in the NCCN definition; however, physiological aspects of distress are not included. Physical problems are included on the Distress Thermometer (DT) screening tool as a checklist with 21 items, in addition to the numeric rating scale (NCCN, 2013). In the absence of definitions for distress, descriptive terms that reflected components of the definition or synonyms were used. Ferrell et al. (2003b) conceptualized four broad thematic areas which were useful for categorizing distress: (1) psychological, (2) social, (3) spiritual well-being, and (4) physical. Although it may be helpful to categorize distress, the literature does not generally limit discussion to one aspect of the concept of distress. Many of the terms were used interchangeably. The following sections explore the different ways distress was identified, including distress as psychological

phenomena, distress as psychosocial phenomena, distress as spiritual phenomena, and distress as physiological phenomena.

### **Categories of Distress**

#### **Distress as psychological phenomena.**

According to the NCCN definition (2013), psychological distress includes cognitive, behavioral, or emotional aspects and is identified as anxiety, depression, coping, vulnerability, sadness or fear, the presence of disabling problems, or panic. While all the above terms were used throughout the literature, anxiety and depression were the most commonly identified terms when distress was discussed and measured. The distinction between the diagnostic terminology and lay meanings for these terms was rarely elaborated. Several studies examined the impact of mental health services on the experience of distress in women with ovarian cancer.

#### ***Anxiety and depression.***

Goncalves, Jayson, and Tarrier (2008) focused on distress as psychological phenomena and, during the treatment and follow-up periods for women with ovarian cancer ( $N = 85$ ), found anxiety and depressive symptoms present after a recent diagnosis. Psychological morbidity rather than temporary distress experiences were classified as “non-cases,” “occasional cases,” and “stable cases.” Seventy-four percent of the participants scored in the clinical range of anxiety as measured by “cases” or “occasional cases” on the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and 45% scored as depression “cases.” In a mixed method study conducted by Matulonis et al. (2008) with 58 ovarian cancer survivors, findings indicated that 40% of the participants had higher distress measures than the norm for medical patients. In addition, 26% of the scores suggested post-traumatic stress disorder. Sukegawa et al. (2006)

reported on three case studies of post-traumatic stress disorder in women with gynecologic cancers (two of the case studies included women with ovarian cancer) and as a result, recommended assessments with appropriate referrals for treatment for patients with gynecologic cancer.

Sukegawa et al. (2008) examined anxiety and psychiatric disorders in women prior to surgical staging for ovarian cancer ( $N = 27$ ). For analysis, the women were grouped according to results of the assessments as “adjustment disorder” or “nonadjustment disorder” and, then, by the results of the surgical staging as malignant or benign. One third of the women were diagnosed with adjustment disorders, and 77.8% scored high on anxiety. Concerned with mental and physical quality of life in women with gynecologic cancers, Suzuki et al. (2011) examined anxiety and depression in Japanese women ( $N = 214$ , including 73 with ovarian cancer) and found depression in 55.1% of their study’s population.

### ***Mental health services.***

Another psychological emphasis on distress was in the evaluation of the use of mental health services. For example, Levine and Silver (2007) evaluated the use of psychosocial services among women diagnosed with gynecological cancers ( $N = 53$ ). Twenty-three of the women in the study’s sample (47% of whom were diagnosed with ovarian cancer) completed assessments at all four of the following time points: baseline, three, six and twelve months. The services most widely used by the women were the nurse practitioner, a gynecological cancer support group, a hair consultant, and guided imagery sessions. Half of the women reported that the nurse practitioner’s education about treatment side effects, body image, and sexuality were helpful. This study linked the women’s distress to poor prognosis, anxiety and depression, and

difficulties with work and relationships. Results indicated that 34% of the study participants were taking psychotropic medications, 7% had undergone individual counseling, 4% reported receiving religious counseling, and 8% attended group therapy. In general, the participants' psychological distress decreased over time, as did quality of life. Levine and Silver (2007) acknowledged that their study's small sample size and the use of different measures for anxiety and depression prevented strong conclusions for their findings.

Norton et al. (2004) investigated psychological distress among a population of women with ovarian cancer ( $N = 143$ ) and found that more than half of the participants reported high levels of distress but that most were not using mental health services or medications. Fitch, Gray, and Franssen (2000), in a study of women with ovarian cancer, selected a subset of women 45 years old and younger ( $n = 39$ ) from a larger study ( $N = 315$ ). Two thirds of the women reported alterations in lifestyle, which included physical changes, work changes, and a healthier lifestyle with a more positive attitude. The authors reported that approximately one-half of the women experienced a negative impact on their mental health. According to the participants, they received help with physical problems, such as treatment for side effects and pain, but did not receive as much help for psychosocial issues, such as fear of cancer recurrence, feeling isolated, infertility, and sexual concerns. Based on the findings of Norton et al. (2004) and Fitch et al. (2000), it is not clear if the use of mental health services to relieve distress among women with ovarian cancer related to the services being readily available or solely due to the choices made by women to utilize those services.

In a secondary analysis of a study conducted by McCorkle et al. (2009) in post-surgical women with gynecological cancers ( $N = 123$ ), O'Sullivan et al. (2011) focused on the sub-

sample of women who were diagnosed with ovarian cancer ( $n= 32$ ). The researcher's stated purpose was to identify characteristics of women who rated their distress high ( $\geq 4$ ) or low ( $\leq 3$ ) on the DT. They noted that the women in the high distress group ( $n = 18$ ), who were seen by a psychiatric advanced practice nurse over a six month period, reported a variety of mood, anxiety, adjustment, and psychiatric disorders (O'Sullivan et al. 2011). Power, Brown,& Ritvo (2008) used semi-structured interviews to examine coping strategies and communication among women across stages and phases of epithelial ovarian cancer ( $N = 30$ ). Epithelial ovarian cancer diagnosed as stage IV has an 18% five year survival rate (ACS, 2014). Significantly, the researchers noted that they observed distress despite participants' reports of successful coping. They concluded that women needed support, particularly after the initial diagnosis, but also throughout the treatment process. The authors suggested that trained professionals, who could provide psychological counseling, would be beneficial for support.

### **Distress as psychosocial phenomena.**

Using a phone interview methodology, Swenson, MacLeod, Williams, Miller, and Champion (2003) asked the following semi-structured questions of 109 ovarian germ cell cancer survivors. Germ cell ovarian cancer is more frequently diagnosed in younger women and when diagnosed as stage IV, has a 55% five year survival rate (ACS, 2014).

(a) What would have been most helpful for you during the diagnostic and treatment period? (b) What would be helpful for you now as a cancer survivor? (c) What, if anything, is the most significant challenge or problem for you now related to having had cancer?, and (d) What else would you like to tell me about your cancer experience? (p. E58).

The authors reported that narrative analysis of the study participants' responses yielded four themes, i.e., "Celebrating illness," "Receiving empathetic affirmation," "Mourning losses," and "Valuing illness" (p. E59). The first two themes were proposed as reflecting the psychosocial experience of the participants. Swenson et al. (2003) noted that the use of the term "celebration" in this context did not indicate happiness or joy, but rather, recognition or awareness of the significance of the life event for the participants. They quoted one participant as stating that the most significant challenge was "carrying the burden of the experience without family support and never having my family celebrate my survival" (p. E60). The authors further noted that another participant would have liked to have been able to talk about her experience with her family. A second theme reported by the authors, i.e., "empathetic affirmation," was reported as reflecting the women's desire to engage with their family in ways that acknowledged and supported their experiences. The authors noted that more than half of the study participants reported sadness and depression as well as problems with memory and concentration as part of their experience of being diagnosed with and treated for germ cell ovarian cancer. findings which are similar to the psychological experience of distress as discussed in the previous section.

Cain et al. (1983), investigated the psychosocial impact on women diagnosed with a gynecological malignancy ( $N = 60$ , 25% of the 60, with ovarian cancer). Data collected included reports of physical symptoms, responses to questionnaires and structured interviews by social workers. Physical factors affected the women's ability to function in their social roles, including their work inside and outside the home. The authors found that only 3% of the participants were not depressed (Cain et al. 1983). Bodurka-Bervers et al. (2000), in a secondary analysis of data obtained for a validation study of the Functional Assessment of Cancer Therapy-Ovarian



(FACT-O) (Cella et al., 1993; Basen-Engquist et al., 2001) sought to identify the prevalence of anxiety and depressive symptoms in study participants with ovarian cancer ( $N=246$ ). They found levels of anxiety and depression higher than in the general population and also higher in women who self-reported poor performance.

In an ethnographic study, Ferrell, Smith, Ervin, Itano, and Melancon (2003) concluded that women with ovarian cancer were concerned about psychosocial issues ( $N=21,806$ ,  $n= 776$  comments on social well-being,  $n= 251$  comments on social support,  $n=146$  comments on family relationships,  $n=74$  comments on employment and returning to work). Illustrating the psychosocial concerns, the investigators reported one participant's comment: “. . . it seems the hardest part of this illness is having those who love you worry so much. It's hard to see them hurt and trying to hide their fears” (p. 658). Ferrell, Smith, Ervin, et al. (2003) reported that women experience frustration “with the lack of information regarding ovarian cancer, compared to more prevalent diseases such as breast or prostate cancer” (p. 653). Power et al. (2008) identified a core theme for participants ( $N=30$ ) in their semi-structured interviews of women with ovarian cancer and identified this theme as “Belief Ovarian Cancer is Understudied and Under-Recognized” (p. 374). The authors quoted one participant as stating, “Of course breast cancer is the most popular thing that you read about all the time... ovarian you don't hear that much” (p. 374).

### ***Isolation.***

According to the NCCN (2103) definition of distress, social or psychosocial issues include social isolation. In an ethnographic study by Ferrell et al. (2003b) ( $N=21,806$  newsletter contributions,  $n=776$  comments about social well-being), the researchers reported that one

participant expressed her feelings of isolation, quoting her as stating, “I watch my children grow up, and it seems as though everyone is moving and I am sitting still” (p. 1068). Ferrell, Smith, Ervin, et al. (2003) analyzed the same data and reported another participant comment as also reflecting the feelings of isolation, quoting her as stating, “Through the surgery [and] beginnings of chemotherapy-even with the wonderful support of family and friends- the general sense has been one of being alone” (p. 651).

Howell et al. (2003a) reported on Canadian women’s ( $N=18$ ) experience of living with ovarian cancer. The participants indicated that their day-to-day lives, including their family relationships, functional and social roles, and employment were negatively impacted. They expressed fear for their husbands and children as well as for themselves due to their diagnosis of ovarian cancer. The authors noted social losses were evidenced by the following statement from one of the study participants,

[B]ecause the cancer has progressed, I don’t have the energy. I can’t do the things I used to do. I have given up an awful lot in the way of exercise classes, going out socially. My sex life has just about disappeared, I would say in the last six months, but that is because of the symptoms of the ovarian cancer (p. 3).

The authors noted that for many study participants, being unable to continue working and experiencing the loss of social relationships also impacted their quality of life and added to their distress (Howell et al., 2003a). Distress was reflected in their expressed concerns, such as having the “stigma of cancer” (p. 7), living with uncertainty, having a fear of the unknown, facing death, and experiencing lack of control.

Using a descriptive phenomenological approach, Akyüz, Güvenc, Ustünsöz, and Kaya (2008) interviewed Turkish women with gynecologic cancer ( $N = 19$ , including five with ovarian cancer) and their partners. The researchers found that the women's concern for the well-being of their loved ones was a significant theme and that social support was an important factor for decreasing distress. The authors noted that participants remembered that experiencing the diagnosis of cancer was traumatic and reported that they had many physical and psychosocial difficulties. According to the researchers, one participant with ovarian cancer expressed the following ambivalent psychosocial concerns,

I don't want to join any group. Everyone asks what happened and how it happened. It makes me feel bad. They wish me good health. But I don't want to respond. Sometimes I want to get rid of these feelings and talk to a friend (p. 244).

The woman's partner noted, "Previously we used to go to activities with friends, go to the theatre and go for walks. She was very tired. It is also not nice to be exposed to the questions of others" (p. 244).

### ***Social support.***

In the study by Akyüz et al. (2008) the researchers found that Turkish women's concern for the well-being of their loved ones was a significant theme and that social support was an important factor for decreasing distress. Participants reported reassurance by their husbands who told them that "We'll go through this together" (p. 245). In a study conducted by telephone interview, Lobchuk and Bokhari (2008) examined correlations between perceived social support, physical symptoms, and psychological distress in a Canadian ovarian cancer population ( $N = 13$ ). They found lower levels of anxiety and depression in patients with greater perceived support.

They recommended that healthcare professionals pay “greater attention to the interpersonal rather than the individualistic processes of stress and coping in patients” (p. 813).

### ***Impact on the family.***

The concept of the patient’s concern for others was often included as an aspect of cancer-related distress. Using a self-report questionnaire to examine the psychosocial needs in outpatient cancer patients ( $N= 188$ ), Liang, Dunn, Gorman, and Stuart-Harris (1990) found that “family” was the patients’ first concern in a list of eight “worries,” followed by “dealing with emotional distress” and by “getting information” (p. 1001). Maughan and Clarke (2001) used a mixed methods approach in women with gynecological cancer ( $N= 36$ ;  $n=19$  intervention,  $n= 17$  control). These investigators were interested in (a) measuring psychological, social, and sexual adaptation following major pelvic surgery, (b) examining the influence of a nursing intervention, and (c) exploring the lived experience of illness following gynecological cancer. According to the authors, all of the interviewed participants in the qualitative part of the study reported disruptions to their “social world” (p. 225) and “future disorientation” (p. 226) as well as concern for the effect of the illness on their family. For those women who were childless and desired children, Maughan and Clarke reported a particularly difficult adjustment and quoted one participant as saying “The absolute worst thing is not being able to have kids. They took away my cancer and with it my future. What am I going to do with the rest of my life now?” (p. 226). Cesario, Nelson, Broxson, and Cesario (2010) conducted a descriptive survey using an on-line interview with women with ovarian cancer ( $N = 360$ ). The researchers found that the women’s concerns were related to their developmental stage of life. For example, women in younger adulthood were more focused on the loss of childbearing and the impact on their relationships,

whereas older adult women expressed anticipated loss in not being able to watch their grandchildren grow. In the study by Akyüz et al. (2008), the researchers specifically examined the experiences of Turkish women with gynecologic cancer and their partner. They identified the theme “effect of cancer on family life”, illustrating it with the follow study participant quote,

My husband and my daughter are doing all they can. My daughter is getting very tired with housework, cooking, etc. I am sad because I am preventing her from studying and I feel as though I am having a negative influence on her future (p. 244).

In a study with women who were diagnosed with ovarian cancer, using ethnographic data ( $N=21,806$ ,  $n= 766$  comments on social well-being), Ferrell, Smith, Ervin, et al. (2003) reported participant comments which described ovarian cancer as “a ‘storm’ that had blown through and burdened their families with new responsibilities, limitations and fear” (p. 655). Ferrell et al. (2003b) also noted that participant comments reflected fear of cancer-related genetic implications for family members and in a report by Ferrell, Smith, Juarez and Melancon (2003) ( $N= 21,806$ ), the authors included a participant quote to illustrate the point.

My mother died at age 53 from ovarian cancer. I was 13 years old at the time, and I watched my mother die a horrifying death. Her death left an unforgettable impact on my family. My sister and I lived with the knowledge that ovarian cancer could strike us. My sister had a hysterectomy at the age of 46. She was experiencing some minor problems but opted for surgery to eliminate any possibility of cancer. So, that leaves me (p. 256).

Thus, according to the research studies, women experienced distress when they observed the impact on their families including the loss of the ability to have children, the disruption to family dynamics, and fear related to potential issues of heredity of ovarian cancer.

### ***Changes in role and functional performance.***

Ferrell, Smith, Ervin et al. (2003) analyzed ethnographic data ( $N= 21,806$ ,  $n= 766$  pertaining to social well-being) consisting of newsletter correspondence from women with ovarian cancer and found that employment and financial issues were a concern. They reported that one woman wrote,

I am a professional woman. I traditionally work 40-45 hours per week without blinking an eye, come home, take care of the kids, pay bills, etc., etc., etc. Now, I've been on disability since my surgery and am ready to climb the walls being home. My kids love it, but I feel more productive at work (p. 657).

Norton et al. (2005) found that, in an ovarian cancer population ( $N = 143$ ), 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. Power et al. (2008) used semistructured interviews to examine coping strategies and communication in a sample of women with ovarian cancer ( $N = 30$ ). These investigators reported that women's responses indicated a need to make lifestyle adjustments related to their decreased functional abilities with one participant quoted as saying "I have to get used to another type of lifestyle" (p. 376).

### ***Relationships with healthcare providers.***

Ferrell et al. (2003a) analyzed ethnographic data ( $N=21,806$ ,  $n= 776$  pertaining to social well-being) consisting of newsletter correspondence from women with ovarian cancer and suggested that healthcare professionals address the social issues that affect women with ovarian

cancer. In a longitudinal study, Von Gruenigen, Frassure, Jenison, Hopkins, and Gil (2006) were able to assess women treated with ovarian cancer ( $N=42$ ) prior to hysterectomy ( $n=21$ ) and prior to chemotherapy ( $n=21$ ) and then at three and six months. They obtained baseline quality of life, functional well-being, dietary and exercise measures, and Complementary and Alternative Medicine (CAM) use. Quality of life scores decreased during chemotherapy, but use of CAM increased during chemotherapy. While supportive of women's efforts to improve their sense of well-being by using CAM, the authors expressed concern that women needed appropriate education regarding the potential use of unproven alternative therapies in place of treatments that may have better evidence-based support.

Cain et al. (1983) investigated the psychosocial impact on women diagnosed with a gynecological malignancy ( $N = 60$ , with 25% ovarian cancer). Data collected included reports of physical symptoms, responses to questionnaires and structured interviews by social workers. These researchers reported a significant finding of their study was that the participants preferred face-to-face interaction over telephone communication when learning about their diagnosis. The 25% of participants who were informed by telephone described the experience as "frightening"

Fitch et al. (2003) focused on women's ( $N=18$ ) perspectives on treatment and decision-making post diagnosis with ovarian cancer. The researchers identified that the initial treatment plans were overwhelming, the women's involvement in treatment decision-making was minimal, and that treatment had many side effects and complications. Fitch et al. (2003) concluded that symptom management was essential for optimal function, performance, coping, and decision-making. In addition, they commented on the need to determine women's preferences for involvement in decision-making because some women in the study expressed that they had

preferred to be more involved. Fitch et al. (2002) focused on women's ( $N=18$ ) reflections on their diagnosis and identified that these participants reported difficulty in getting a diagnosis. Combined with the vagueness of their pre-diagnostic symptoms was the frustration of having their concerns and fears dismissed by the healthcare professionals. The researchers reported that they detected a sense of anger over the delay in diagnosis which resulted from the healthcare provider's failure to listen to their concerns. Another communication difficulty reported by the participants in the study by Fitch et al. (2002) was the confusing use of unfamiliar medical terms which left the participant unsure about the information provided by the healthcare professional. Howell et al. (2003b) identified that recurrence was part of the lived experience for these women ( $N=18$ ). One theme that emerged demonstrated that women were "waiting for recurrence" (p. 13). The authors recommended that healthcare providers extend sensitive attention to the women's needs at this time because of a poor prognosis. In a literature review of biobehavioral outcomes related to psychological interventions, Andersen (2002) concluded that emotional distress, resulting from unrelieved stress may negatively impact compliance with treatment and disease outcomes.

### **Distress as spiritual phenomena.**

Spiritual distress is included in the NCCN (2013) definition of distress. Akyüz et al. (2008) identified a theme of "finding meaning in disease" (p. 245). These authors reported that study participants ". . . learning that they might die meant that they had felt drawn to re-evaluate their relationships with God" (p. 245). Gioiella, Berkman, and Robinson (1998) studied women with gynecologic cancers ( $N=18$ ,  $n=11$  with ovarian cancer). They used the Functional Living Index- Cancer (FLIC; Schipper, Clinch, McMurray & Levitt, 1984) and the Spiritual Well-being



Scale (SWB; Paloutzian and Ellison, 1982) and reported that women with ovarian cancer had responses that indicated lower quality of life, spiritual, existential, and religious well-being than women with other cancers. Using a grounded theory approach, Halstead and Hull (2001) examined the process of spiritual development in women with ovarian cancer, breast cancer, and non-Hodgkin's lymphoma ( $N = 10$ ). The authors identified the experience of these women in terms of paradox as they struggled to make sense of contradictory emotions and experiences. The women had to determine the personal meaning of their experience with cancer and reconstruct their perspectives to accommodate the uncertainty of their futures. Based on their findings, Halstead and Hull (2001) suggested that assessing and supporting spiritual practices would be beneficial for women diagnosed with and treated for cancer. Canada et al. (2006) investigated the role of religion or spirituality (R/S) and active coping for women ( $N=129$ ) with ovarian cancer, just before a course of chemotherapy. This research team found significant correlations between R/S and active coping ( $r=0.23$ ,  $p<0.05$ ), quality of life ( $r=0.25$ ,  $p<0.05$ ), emotional well-being ( $r=0.24$ ,  $p<0.05$ ), functional well-being ( $r=0.28$ ,  $p<0.01$ ), and ovarian concerns ( $r=0.27$ ,  $p<0.01$ ). Quality of life and physical and functional well-being were reported by the authors as highly correlated (physical  $r=0.84$ ,  $p<0.01$ ; functional  $r=0.87$ ,  $p<0.01$ ). The investigators also acknowledged the need for clinical treatment to include attention to spiritual needs and resources. In a grounded theory study, Reb (2007) found that women with advanced ovarian cancer ( $N=20$ ) "relied on prayer for strength and to help keep their fears under control" (p. E73). This author identified three phases of "transforming the death sentence" including: (1) shock; (2) aftershock; and (3) rebuilding (p. E73) and connected hope as a spiritual element that facilitated the transformation. Cesario et al. (2010) used a virtual online interview to ask women diagnosed

with ovarian cancer ( $N=360$ ) about their “worries” (p. 610). These authors found that, among their participants, recurrence and fear of death were the most common worry, which the researchers defined as “unrelenting thoughts regarding threats to health and well-being” (p. 614). They reported that one participant was emphatic in her response to the question about “worry” and quoted her written comment as: “REOCCURRENCE!!!!!!!!!!!!!! How close I came to dying” (p. 614). Ferrell et al. (2005) recruited participants from the mailing list of an ovarian cancer newsletter ( $N=1383$ ). “Recurrence” ( $n=774$  or 56%) and “death or dying” ( $n=122$  or 9%) were the first two of the ten most frequently mentioned concerns.

Spirituality was also addressed in an ethnographic study by Ferrell, Smith, Juarez et al. (2003) ( $N= 21,806$ ,  $n= 844$  comments related to spirituality and the meaning of illness). The researchers noted that these comments were written by women who said they relied on their spirituality to give meaning to their cancer experience and to provide hope through a life-threatening illness. The researchers reported that one participant commented, “I keep repeating to myself ‘God is in control.’ It’s been the only thing I do know for sure in the midst of the chaos in my life!” (p. 251).

### **Distress as physiological phenomena.**

#### ***Symptom experience.***

Physiological symptoms can be related to the progression of ovarian cancer as well as the effects of the treatments and may be experienced as distressing. Portenoy et al. (1994a) considered the effect of pain on distress and concluded that multiple symptoms contributed to both the pain and distress experiences in women with ovarian cancer. Among this study’s participants ( $N = 151$ ), 62% reported pain prior to diagnosis, with 74% locating the pain in the

abdomen or pelvis, although some participants indicated pain occurred in the lower back, rectal, or genital areas. As previously noted, researchers did not always make clear distinctions between the types of distress and in this study, psychological distress was defined as the components of the Memorial Symptom Assessment Scale (MSAS; Portenoy et al. 1994b) which included the items of “worrying”, “feeling sad”, and “feeling nervous” (p. 912) and were among the most prevalent. These components of distress were reported by greater than 50% of the participants and further as “highly distressing” by one fifth or more. The MSAS includes thirty-two physical and psychological symptoms, measuring them in respect to “severity, frequency and distress” (p. 908). Liu, Ercolano, Seifert, and McCorkle (2010) conducted a secondary analysis and used data from an earlier (McCorkle et al. 2009) longitudinal interventional study for women with gynecological cancers ( $N = 66$ , 59% with ovarian cancer). Measures included the DT (NCCN, 2013), and a self-report symptom checklist of ten common symptoms (pain, fatigue, bowel dysfunction, depression, anxiety, disturbed sleep, hair loss, lack of appetite, nausea, and numbness (p. E136). These authors found statistically significant associations between emotional distress and pain ( $p < 0.01$ ), depression ( $p = 0.01$ ), fatigue ( $p = 0.05$ ) anxiety ( $p = 0.01$ ), and the total number of symptoms ( $p < 0.01$ ). The authors reported that the participants experienced high levels of distress and the mean DT score was 4.91 ( $SD = 2.8$ ). The original study was a randomized clinical trial in which researchers tested a specific nursing intervention on enhanced quality of life and post-surgical outcomes in women with gynecological cancer. The purpose of the secondary analysis by Liu et al. (2010) was to describe the pattern of symptoms and examine relationships between the variables of demographic information, disease characteristics, and the symptoms that women reported (p.E134). Norton et al. (2005) found that, in an ovarian cancer

population ( $N = 143$ ), 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. In an ethnographic study, Ferrell et al. (2003a) ( $N=21,806$  newsletter contributions;  $n=677$  physical well-being) examined the data for comments related to the experience of symptoms. They concluded that symptoms negatively impacted quality of life among women with ovarian cancer. Women in the study by Ferrell et al. (2003a) reported having had pre-diagnostic symptoms and experiencing distress due to their delayed diagnosis. Post-diagnostic symptoms included pain, fatigue, gastrointestinal effects, and menstrual and fertility changes. The women in this study also reported that they considered complementary and alternative therapies as significant treatments.

### ***Sexuality.***

Sexual concerns were another aspect of the physiologic experience of distress in women with ovarian cancer. In a review of the effects of treatment for gynecologic cancer on female sexuality, Andersen and Hacker (1983) noted that although sexual issues may not be considered a priority compared to life-threatening concerns of having cancer, improving quality of life for survivors, according to the authors, is critical. Several studies mentioned sexuality concerns and changes due to cancer in general, but the following investigations focused on this area of distress for women with gynecological or ovarian cancer, specifically. Findings from research conducted by Stead, Fallowfield, Selby, and Brown (2007) revealed frequent sexual problems in their sample of women with ovarian cancer ( $N = 15$ ). Almost every woman who had been sexually active prior to the diagnosis reported that they experienced distressful changes in their level of

sexual activity. Kornblith et al. (2010) examined the long-term adjustment of 42 ovarian cancer survivors (mean = 6.1 years postdiagnosis) and found that 29.8% of the participants reported emotional problems (p. 464) and 44% of those who responded to the question about sexual problems reported decreased interest in sexual activity, which prompted the authors to recommend that women with these problems be screened for distress. In a qualitative descriptive study that used individual interviews ( $n = 8$ ) and focus groups ( $n = 5$ ), researchers concluded that all the women's sexuality was altered by the experience of ovarian cancer and recommended that education about anticipated changes would be helpful (Wilmoth, Hatmaker-Flanigan, LoLoggia, & Nixon, 2011). In a qualitative arm of a mixed methods study, Maughan and Clarke (2001) evaluated the effect of "an innovative psychosexual intervention by a clinical nurse specialist" (p. 221). Participants ( $N=36$ ;  $n = 19$  treatment group,  $n = 17$  control group) with gynecologic malignancy were randomly assigned to the treatment or control group. The intervention included emotional and educational support at the time of diagnosis as well as before and after surgery, with specific discussions of sexuality and the resumption of pre-diagnostic roles and activities. The authors reported that the women experienced uncertain futures and were concerned about sharing their diagnosis with others and about infertility, the effect of their illness on their family, survivorship issues, and sexuality.

### **Summary**

In summary, while research findings have indicated that women diagnosed with and treated for ovarian cancer may experience distress, research to date has not focused directly on the experience as seen from the perspective of the women diagnosed with this disease. Infrequent use of definitions for distress and inconsistent use of terminology have also contributed to the

difficulty in investigating their experience of distress. Given these limitations, the study contributes both to the understanding of the experience of distress in women diagnosed with ovarian cancer and to the research literature related to psychosocial needs of cancer patients.

## CHAPTER THREE METHOD

### Study Design

The research project used a qualitative study design with a modified Glaserian (Glaser & Strauss, 1967) Grounded Theory methodology to explore the research question: “What do women with ovarian cancer want others (spouse/significant other, family, friends, and healthcare providers) to know about their experience of distress during diagnosis and treatment?” The purpose was to discover, from the substantive data, a conceptual understanding of the experience that could lead to the development of a conceptual model and potentially the creation of theoretical framework to generate future research in women diagnosed with and treated for ovarian cancer.

### Study Sample

The study sample was recruited from local gynecological oncologist practices and an ovarian cancer support group with a local e-mail list in the Richmond and Central Virginia geographical area. Prior to enrolling participants, the investigator received approval of the study by the Institutional Review Board (IRB) of Virginia Commonwealth University (Appendix A). Additional IRB documents are included in the appendices reflecting alterations related to the relocation of a key referring physician (Appendix B), adjusting the inclusion age range from “18-60” to “over 18” (Appendix C), a change in the primary investigator (appendix D), and the addition of recruitment sites to include an ovarian cancer support group (Appendix E) and Bon Secours Richmond Health System (Appendix F).

Brochures and print/e-mail invitations (Appendix G) describing the study and providing the investigator's contact information were disseminated as part of the recruitment strategy. An interview was arranged with those women who expressed an interest in the study and who met inclusion criteria. Criteria for inclusion were (a) aged 18 years and older; (b) diagnosed with ovarian cancer (Stages I, II, III, IV, or recurrence); (c) any race or ethnicity able to speak and understand English; (d) available for an in-person interview in the Richmond and Central Virginia geographical area, planned for a convenient time and place such as during chemotherapy, before or after a medical appointment, or at a public location such as a library conference room or coffee shop; and (e) agreeing to an individually audiotaped interview, expected to take between one to two hours.

## **Method**

### **Glaserian grounded theory.**

Grounded theory has a relatively short, but dramatic history. The original creators, Glaser and Strauss (1967) found that their approaches differed over time. When Strauss collaborated with Corbin (1990) to clarify the method, Glaser responded with additional volumes of his own. *Basics of Grounded Theory Analysis* (1992) is explicitly a rebuttal to the work by Strauss and Corbin. Glaser (1992) described Strauss and Corbin's (1990) method as "Full Conceptual Description" (p. 102) suggesting that it was a new but different method. Glaser, still an active researcher, has continued to clarify and refine the original method (1965, 1978, 1992, 2008 and 2012). Walker and Myrick (2006) explored the history of the development of the grounded theory method and the differences between Glaser and Strauss. Walker and Myrick noted that both researchers use the components of "coding, constant comparison, questions, theoretical



sampling, and memos in the process of generating theory” (p. 550). A glossary of terms has been included (Appendix H). However, these authors observed that Glaser and Strauss each emphasized certain components differently. For example, Strauss provided a more extensive or formalized coding system, while Glaser preferred to focus on emergence. Glaser stated that “Forcing organization or integration on data never works too well in capturing essence, while letting integration emerge always does” (Glaser, 1992, p. 90). The original work by Glaser and Strauss (1967) with clarifications by Glaser was determined to be best suited to explore the experience of distress by asking women what they would like others to know, thus contributing the women’s perspective to understanding the experience of being diagnosed with and treated for ovarian cancer.

The purpose of grounded theory, according to Glaser and Strauss (1967), is discovering or generating theory from a real life situation. The theory *fits* or explains the substantive content or what the investigator has observed, but may not be generalizable to other populations or situations. For grounded theory methodology, the investigator is an integral part of the process, contributing memos to the data and taking the substantive data to an abstract and conceptualized point where theoretical codes emerge. To accomplish this, the investigator does not eliminate personal contribution, but does make an effort to be aware of and minimize preconceived conclusions. Another component of grounded theory methodology includes hand sorting of the theoretical codes and memos into groups and then combining like groups. Those groups which do not represent the developing theory are eliminated. The substantive grounded theory which emerges represents the relationships and latent or hidden patterns between the subcategories. The grounded theory process is intended to bring the abstractions and conceptualization from the

substantive data collection into a theory which *fits* and is meaningful for the data and phenomenon it reflects. Grounded theory is a dynamic process and should a theory emerge, modifications may still be desirable including theory testing, to determine if it is applicable to other situations and populations. The purpose for this investigation was to discover, from the substantive data, a conceptual understanding of the experience, leading to the development of a conceptual model and potentially a theory which describes or explains the experience of distress in women diagnosed with and treated for ovarian cancer

Glaser (1992) described the process of grounded theory “as a few neutral questions and the constant comparative method” (p. 58), though he acknowledged that skill developed with practice. The process begins with theoretical sampling when the investigator asks the neutral question “which groups?” to determine population. The question “what is going on in this situation?” contributes observations and then, with the constant comparative method, also contributes to the emergent themes and categories with “theoretical relevance” (Glaser and Strauss, 1967, p. 49). The coding process starts at the basic substantive level asking what is present in the content. For example a unit for coding might be related to the subject, verb, or object of the sentence, or phrases that are significant or are repeated. The next level of coding takes the substantive code and asks what is the meaning of the code on a more abstract or conceptual level.

Discoveries during data collection may lead the investigator in a new direction, or may help refine the emerging conceptualizations, contributing to the development of the theoretical codes which become the subcategories of the theory development. Multiple data sources, discovered through theoretical sampling, are considered legitimate. The memos, subcategories,

properties, and ultimately the grounded theory must be traceable back to the substantive data and reflect the basic social process or observed phenomena.

**Grounded theory: modified.**

Glaser considered grounded theory to be a clear method with a few steps, specifically asking key questions and using the constant comparative method. However, the research method for this study required modification. For example, according to Grounded Theory as developed by Glaser and Strauss (1967), the investigator is to approach an area of interest with naiveté; the purpose of which is to provide for objectivity in data collection. It was not possible for the investigator of this study to begin with “naiveté” because of having practiced for more than 15 years as a women’s surgical oncology nurse. Additionally, in preparation for development of background and significance for this study, the investigator completed and reported an extensive literature review related to distress and ovarian cancer. Finally, as a result of obtaining this background information, the investigator began the study with a research question rather than letting the question emerge from the data. A decision trail (Appendix I), reflective journal, reflexivity, bracketing, and peer review were employed to control for these limitations. The methodological procedures of grounded theory such as conceptualization and hand sorting also helped to limit the influence of preconception since unsupported content was often not congruent with substantive data.

Another modification to the grounded theory method involved the data collection process. The use of audio taped, professionally transcribed interviews, initiated with a written, standardized, interview guide (appendix J) differs from the Grounded Theory Method of Glaser and Strauss (1967) who proposed first observation and then initiating participant interviews with

open-ended, unstructured inquiry. For Glaser and Strauss (1967), transcribed interview notes would restrict richness and thickness of the data. However, in this case, using printed transcripts allowed the investigator to confirm that conceptualizations came from the participant content and not from preconception, thus contributing to trustworthiness of the data.

### **Data collection.**

Following IRB approval in January 2013, the first three interviews were arranged and completed in February, 2013. A factor which limited recruitment was the relocation of the study's primary referring physician to another practice location. This required making protocol changes to enhance recruitment; these changes included adding additional recruitment sites and expanding the age criteria from the limitation of "ages 18 to 60" to a larger potential age range of anyone "over the age 18". Upon receipt of IRB approval of the amended protocols (Appendix C,D,&E), additional participants were recruited each month until saturation was observed with interview number 10, and confirmed with interview number 12, in August, 2013. Data for analysis included the professionally transcribed audio-taped interviews and memos created by the investigator before, during, and after the interviews. Once transcribed, twelve interviews contributed 528 pages of data with a mean of 44 pages per interview. Demographic information was collected with a form (Appendix K) and provided descriptive information about the study sample.

According to Glaser and Strauss (1967), essential elements of grounded theory generated by the constant comparative method include conceptual subcategories and their properties and the hypothesis or the propositional relationship of the categories. Following this method, the process to identify these elements included substantive, line by line coding, using abstraction and

conceptualization to develop theoretical codes that were then hand sorted into groups of like variables. These groups of like variables were further systematically grouped into subcategories. While the process of this method, as reported here, appears linear, in truth, the operationalization of this method was nonlinear with the investigator constantly returning to the data, reflecting on the process, memoing, and bracketing so as to capture all aspects of the grounded theory developmental process. For this study, the investigator maintained a reflective journal and created memos throughout the data collection and data analysis process. The collection of data continued until theoretical saturation was determined. Theoretical saturation was defined as no new categories or theoretical codes emerging from the collected data. A conceptualized or theoretical model was created (Figure 1) and propositions formulated about the relationships of the subcategories.

#### **Data preparation for analysis.**

In order to identify codes and prepare for constant comparative analysis, the professionally transcribed audio taped conversations were converted to Microsoft Word documents and compared with the tape for accuracy and for non-verbal contributions such as tapping on the table, pauses, or variations in participant's tone of voice. The printed word documents were marked with a coding system and reviewed multiple times.

#### **Data analysis by the constant comparative method.**

Analysis for grounded theory uses the constant comparative method. The method is both simple and complex since coding and analysis occurs at several different levels simultaneously. Listening to the audio-taped content and reading the professionally transcribed interviews provided the investigator the opportunity to identify significant and recurring themes. Glaser and

Strauss (1967) outlined the four stages of the constant comparative method as (a) comparing incidents applicable to each category; (b) integrating categories and their properties; (c) delimiting; and (d) writing the theory. Comparing incidents applicable to each category was achieved through coding the data first at the substantive level and then at the theoretical level. Integrating categories began when the emerging theoretical codes were combined according to similarities and continued until the relevant subcategories were identified. At this time in the process, some conceptualization groups collapsed into others and some were eliminated, thus delimiting the theory. Then the results were written based on the properties of each subcategory along with illustrations from the substantive data and propositions for the relationships were developed.

Glaser (2012) provided direction to keep the analysis grounded in the data at a conceptual, rather than a descriptive level, by asking formal, objective questions, differentiated from preconceived content questions. Keeping with these directions, the investigator reviewed each coded section in this study by asking the questions, (a) “What was the chief concern or problem?” and (b) “What was going on that was an issue?” By asking these questions of the data, the investigator gained insights that contributed to the further development of the theoretical coding and creation of subcategories. This process led to theoretical saturation, meaning no further sampling was required for data collection and analysis, thus providing assurance that the final subcategories and thus the resultant findings were grounded in the relevant data. The result of this data analysis was the emergence of six related subcategories with supporting properties grounded in the data.

### *Coding.*

The first level of coding was substantive coding. Line-by-line coding and reviewing the content at a basic level contributed to the next level of theoretical or conceptual coding of the data. With each new interview, emerging codes were compared. The process included *double-back steps*, meaning the investigator returned to the original data for comparing and added any additional data with theoretical sampling in order to saturate categories and identify relationships (Glaser, 1978).

Glaser's coding process was described by Walker and Myrick (2006) as "an iterative, inductive, yet reductive process that organizes data, from which the researcher can then construct themes, essences, descriptions, and theories" (p.549). The coding process was a means to an end for Glaser and while he differentiated between levels of coding, his primary emphasis was on taking the data from the substantive level to a theoretical level based on observed similarities and differences. Whether it is called substantive, line by line, axial, open, selective, or theoretical, there are different practical levels of coding. All coding in this study contributed to the constant comparative method of analysis by labeling units of content and, according to Glaser (2012), it was important for emergence that it be completed directly by the researcher and not by computer software or by a research assistant. In this study, both substantive and theoretical codes were compared within, between and among interview data sets. Printed copies of the coded interviews were cut apart for sorting.

### ***Memos.***

Memos are intended to provide additional insight and are considered data in the development of a grounded theory (Glaser, 1965). Memos reflect the analytic process of conceptualization and abstraction of the data by the researcher. In this study, the investigator

followed Glaser's direction to stop coding and memo whenever insights happened during the constant comparative analysis process, thus noting that this method contributed to data collection. As part of the data collection process, systematic and spontaneous memoing took place prior to and following each interview, during substantive and theoretical coding, during data analysis, and also while the investigator went about normal daily routines. Again following Glaser's (2012) method of hand sorting the codes and memos into groups, the investigator took printed pages of the memos, cutting them apart, and adding them to the sorted groups described above.

### **Methodological Rigor and Procedures**

A crucial element of the research process in this study was attention to methodological rigor. Careful consideration of human subject's protection, systematic record keeping, the practice of reflexivity, peer reviewer and committee contributions demonstrate the rigor of this research study. Additionally, rigor in qualitative studies is evaluated in terms of credibility, confirmability, dependability, and transferability which are comparable to external and internal validity evaluated in quantitative studies (Schmidt & Brown, 2012). These terms provide some structure to the evolving discussion which began with Lincoln and Guba (1985) about establishing rigor in what was initially called *naturalistic inquiry* (p. 7). Components of their discussion included truth value, applicability, consistency, and neutrality (pp. 289-331). Burns (1989) indicated that rigor is related to methodological congruence with documentation, procedure, ethics, and auditability. Schmidt and Brown (2012) define trustworthiness as the "quality, the authenticity, and the truthfulness of findings" (p. 354). The truth value, quality, authenticity, consistency, methodological congruence, procedural documentation, or creditability



can be compared to internal validity. The applicability, neutrality, ethics, and auditability can be compared to external validity. For qualitative studies, external validity is challenging because the intent is to understand the experience of the individual or specific populations. Sandelowski (1986) helped to more sharply focus the concepts of confirmability and auditability, and Koch (1986) elaborated on dependability. Creswell and Miller (2000) elaborated on the complex issue of external validity in qualitative studies and suggested that it was necessary to consider validity from the differing perspectives of the researcher, the participant, or external reviewers, each of which may be different. Lincoln and Guba (1985) first recommended an audit trail (p. 379) and Koch (2006) suggested a decision trail to provide evidence of reliability in the research process. Glaser (1965) described this as “keeping track of one’s ideas” (p. 444) and advocated using a “codified process for analyzing data” (p. 443) to address concerns of credibility.

### **Credibility.**

Synonyms for credibility include trustworthiness, validity, reliability, and objectivity (Powers & Knapp, 2011). Glaser (1965) stated that the grounded theory method was not “designed (as quantitative methods are) to guarantee that two analysts working independently with the same data will achieve the same results” (p. 438). In this study, issues of credibility were addressed in a number of ways. For example, a committee member with grounded theory expertise assisted with adherence to Glaserian methodology. Peer review helped to identify preconceived or biased assumptions which may have influenced study findings. The peer reviewer was a fellow doctoral student with an interest in grounded theory. The peer reviewer examined the first and fifth interview for accuracy, and the ninth for theoretical content, helping to verify that the coding of the three interviews was representative of the interview content. The

peer reviewer provided a sounding board during the theoretical coding and hand sorting procedures, guided the investigator away from leading questions in subsequent interviews and also provided the opportunity to debrief following intense content from the interview experience. Constant comparative method began with the first interview and continued throughout the analysis. Participants were encouraged to provide as much detail as they were comfortable in sharing and most talked freely prior to, during and following the audio taped interview. Because member checking was not included in the original proposal, peer critique, for relevance of the subcategories only, was sought from a group of women's surgical oncology nurses. They affirmed the relevance of the subcategories for this population. Triangulation, where confirmation of the findings is supported by at least three different sources, contributed to credibility. Findings for this study were acknowledged by the committee member with expertise in the oncology population, as well as with grounded theory method, peer review, and the surgical oncology nurses as having relevance and *fit* for the population. Additional support for the findings was reflected in the review of research literature. Another measure to support credibility was in the process of multiple readings of the transcribed interviews with documented coding. Reflective journaling provided the investigator the opportunity to memo, to think on paper and to document the processing required for data collection. These aspects reflected Glaser's (1978) guideline of prolonged involvement and persistent observation of the investigator which contributed to credibility.

### **Confirmability.**

Confirmability demonstrates a link between the findings and the data (Powers & Knapp, 2011, p. 192). Extensive record keeping and a decision trail (appendix G) were maintained. The

decision trail reflected when changes or modifications to study procedures were required. The peer reviewer and the reflective journal also contributed to confirmability, as well as credibility. The reflective journal recorded dates and contributed a place to record the investigator's pre-formed thoughts which eventually contributed to coding, memoing, and sorting. Potential sources of investigator bias were identified and related largely to the modifications required for dissertation research.

### **Dependability.**

Dependability or reliability (Powers & Knapp, 2011) can be evaluated by the documentation process. Neutrality is a significant scientific perspective contributing to dependability. However, for grounded theory methodology, the investigator is an integral part of the process, contributing memos to the data and taking substantive data to an abstract and conceptualized point where theoretical codes emerge. To accomplish this, the investigator did not eliminate personal contribution, but rather made an effort to be aware of and minimize preconceived conclusions. One potential limitation of this study related to the issue of dependability may be found in the limited nature of time and resources available for the completion of this dissertation research study. That is, due to time and resource limitations, it was not possible for the investigator to include additional interviews, such as family members, nor make observations over time, as suggested by Schmidt and Brown (2012), thus contributing to dependability. However, saturation was identified and confirmed, and the other measures discussed above contributed to the dependability of the study.

### **Transferability.**

Transferability or generalizability is not the immediate goal of grounded theory. Rather, the goal of grounded theory methodology is to generate a theory which reflects the substantive data and thus *fits* the experience of the participants. With modifications and testing, the substantive theory may become a formal theory with more widespread application. Within these boundaries or limitations, “thick description,” represents a component of transferability since it provides content which is “rich in expression and detail” (Powers & Knapp, 2010, p. 188). However, it is important to consider that “full conceptual description” is not the goal of Glaser’s grounded theory method.

To address concerns of rigor in this study, the investigator took care throughout the study, whenever possible, to systematically apply the grounded theory method. Documentation of data was extensive and included printed copies of the coded interviews, summary statements of each interview coding, summaries of the evolving constant comparative analysis, files of hand sorted memos, a reflective journal, and a decision trail. In addition to these aspects, careful attention to human subject’s protection, record keeping, peer reviewer, and committee contributions demonstrated the rigor applied to this research study. With these in place, the study findings emerged from the data, not from preconception or bias of the investigator.

### **Summary**

This study used a modified version of Glaser’s Grounded Theory Method (Glaser & Strauss, 1967) to explore the experience of women with ovarian cancer and what they would like others to know. The six subcategories and their relationships depicted in the conceptual or theoretical model (Figure 1) are reflective of the substantive content of the data provided by 12 study participants who were diagnosed with and treated for ovarian cancer. These significant and

relevant themes help answer the research question “What do women with ovarian cancer want their spouse/significant other, family, friends, and healthcare providers to know about their experience of distress during diagnosis and treatment.”

## CHAPTER FOUR RESULTS

This was a qualitative study using a modified Glaserian Grounded Theory (Glaser & Strauss, 1967) methodology to explore the research question: “What do women with ovarian cancer want their spouse/significant other, family, friends, and healthcare providers to know about their experience of distress during diagnosis and treatment?”

### **Descriptives**

A total of 15 women expressed interest in the study; however three individuals did not meet inclusion criteria and were ineligible for participation. Twelve participants signed consent forms and completed the interviews. Participants ranged from ages 21 to 71 (two women < 40 years; six women between ages 40-60 years; and four women >60 years). Education levels ranged from high school graduate to graduate degrees. Household income levels ranged from less than \$50,000 to over \$100,000. Two participants reported working full- time, one part time, while three have retired, five are on disability, and one is a student. Two participants identified themselves as single, two as divorced or separated, and seven as married. One participant did not answer the question. Ten participants self-identified as Caucasian and two as African American. One also wrote in “Ashkenazi Jew” for further clarification. Data collection also included age and stage at time of diagnosis, though not everyone answered the question. One participant reported receiving a diagnosis of stage I at 46 years of age; one reported stage II after 50 years of age; one reported stage III after 70 years of age; five participants reported a diagnosis of stage III without indicating at what age the diagnosis was made; and one participant was between 50 and 60 years and reported a diagnosis of stage IV ovarian cancer. Disease recurrence was reported by

six participants. All participants indicated surgery was part of their treatment, ten indicated that they had experienced chemotherapy, one had radiation, and five used adjunctive, non-pharmacologic therapies such as massage and colonics.

### **Study Findings**

The outcome of the current study was the identification of the term *existential assault* as a way to describe the experience of what occurs when a diagnosis of ovarian cancer is received and treatment is not only initiated, but lived through. Existential is defined as “Of, relating to, or affirming existence” and assault is defined as an “attack with the threat of bodily harm” (Merriam-Webster Dictionary, 2014). Findings revealed that study participants were describing an assault upon their very existence.

### **Subcategories, Related Properties and Type of Response.**

In this study, after coding and conceptualizing all interview related data, multiple properties emerged that finally resulted in a total of six subcategories. These were labeled as: (a) “Out of the blue like lightning”; (b) “No stone left unturned”; (c) “Knowing what I don’t want to know and not knowing what I want to know”; (d) “Watching you watching me- we are both afraid”; (e) “Talking yet not talking, about death”; and (f) “Now I have to take care of me.” Each participant had a unique experience and yet shared a common conceptual experience. The coded interview content and the memos provided illustrations of the subcategories and are presented in the following sections.

#### ***Out of the blue like lightning.***

Diagnosis was shocking and unexpected news, accompanied by uncharacteristically rapid medical attention with multiple tests, referrals, immediate surgery, and at times, frank

discussions of options and plan of care. One participant stated "...and we felt like this death sentence had been, you know, uh, you know, proclaimed." For most participants, the experience was one of shock and incongruent with their personal healthy self-image. One participant stated, "I'm healthy except for the part where you tell me I'm dying." Participants reported that families experienced the shock as well. A husband's first response was "I don't want to lose you." Non-verbal cues from healthcare professionals, such as the urgency of the medical response, tone of voice, facial expressions, and avoidance of eye contact, communicated the seriousness of the illness. One participant recalled being given the diagnosis over the phone, and mentioned "I could tell by his voice that it was serious." Previous knowledge of and experience with cancer impacted the expectations for these participants. One participant acknowledged hearing "horror stories" and added that "We know the statistics... We know we are dying." Several study participants reported having worked in the medical field and, because of that, reported that they found the medical responses reassuring, even though there was a general sense that "they can't tell me for sure what will happen next or what to expect." Not everyone was able to assimilate the information immediately. For example, one participant stated,

I mean it was just so fast. I'm still taking it in. And I remember waking up the first night in the hospital room realizing that I was talking to myself and what I was doing, I was sobbing and I was saying 'And then they decided it was stage three and then they decided I needed surgery and I'm going to need chemo and...' You know, and I'm just kind of repeating it all to myself so that I'm kind of validating it in my mind.

One participant spoke eloquently about the non-verbal cues.



We watch your every move. So if you are giving an exam and you go “Hmm” that has tremendous meaning for me. When you all walk in the room together with lots of paperwork I know what that means before you open your mouth. Like, so you have to be really aware. I know you’re just getting through your day and you’ve got messages and people waiting on you and your spouse is calling you and it’s just you’re just working... But remember this is the most important thing that has ever happened to your patients, and we watch your everything. And then we go home and we think about it a lot. We try to figure out what you didn’t tell us. So you need to be really careful about that, to not send unintended messages, or if you are sending a subtle message to be aware that you’re doing that too and make sure that the person keeps... you know has... has... the ability to handle, to process and handle it or take the steps that they need to take.

Those participants who were younger in age (i.e., ages 21 and 39) talked about a life interrupted and the repercussions of the cancer and treatment on their present health, their self-image, and their reproductive options. All participants acknowledged the importance of decisions, especially in the areas of how they spent their time and their money. One participant stated,

So you have this terrible disease that’s probably going to shorten your life and shorten it a lot. So then there’s just incredible pressure on what you do with your time. So, if I play this really ridiculous video game right now and it’s sucking up some time, right. I sit in front of the computer and I slay monsters, and right. This is not a very meaningful exercise; it’s not even an intellectually stimulating one, but I’m doing it. Then do I feel really guilty about it like “Oh my God, I only have this many minutes left on the earth

and I just spent 20 of them playing this game”?... Is that a good day? God, I should have done something more important with that time,” you know. And so there’s this incredible pressure on all of your decisions about now that you know, you know how valuable time is. So when you- your decisions about it I think are super-charged with meaning and pressure.

The diagnosis of ovarian cancer was unexpected and altered the lives of these women and their families. The women and their social network, which included their spouse/significant other, family, friends, and healthcare providers, responded by finding the best options which included a search for the most effective treatments as well as making lifestyle changes.

***No stone left unturned.***

The focus shifted quickly to identifying treatment options. One participant reflected “I’ve not left any stones unturned that I know of.” Going for second, third, or multiple opinions, joining clinical trials and researching on the internet was an effort by study participants to find the right doctor and the right treatment to extend their time. Knowing that they were doing everything that could be done was comforting for both the participant and their families. Finding what else was available provided hope for many. These participants were aware that the treatment carried risk and that the chemotherapy was also dangerous, but were willing to do whatever was needed to improve their chances. They expressed the need to know the truth, but also needed to have hope. Many turned to holistic and non-pharmacological treatments.

Surrounding themselves with positive influences and controlling stress was part of their personal action plans. For some this included eliminating negative relationships described as “getting rid of those who had given up on me.” Most were careful about exposure to negative

influences and avoided support groups or internet conversations which increased their fear or anxiety. This self-advocacy was reflected in the comment “it’s either me in control or cancer in control.” When medical resources were exhausted, these participants were willing to consider unconventional alternatives and would seek out treatments at different hospitals with different doctors and look for information on internet sites, actions reflective of “no stone left unturned.”

***Knowing what I don’t want to know and not knowing what I want to know.***

Life was forever changed with the diagnosis of and treatment for ovarian cancer. One participant asked, “How do I live with knowing I’m never **really** going to be OK? I mean you’re OK today, but you live with that threat. It’s like living with a cloud over your head, you know?” A comment by another participant indicated “I knew there was something there,” while others chose to focus on “I just keep doing whatever is next.” Paradoxically, uncertainty brought both stress and some degree of hope, because the participants were aware that survivors of ovarian cancer are rare. One participant asked, “Do I live like I’m going to live or like I’m going to die?” This participant was diagnosed before age 50 and had already experienced recurrence. She wondered about the meaning and purpose for her life as well as whether she should save her money for necessary medical and life expenses or take her dream trip to another continent. In general, participants expressed the need to focus on positive thoughts and avoid negative ones. Superstitious thoughts were shared in a few interviews. One highly educated participant shared that worry seemed to prevent bad things from happening, while others avoided negative thoughts to prevent them from happening. One described her experience as an “emotional roller coaster- never knowing if you are going to get better or worse.” Another participant noted that even good news carried its own level of stress, partly because of the awareness that eventually the news

would not be good. Voice changes and hesitations during the interviews were clues to areas which reflected this subcategory of “knowing what I don’t want to know and not knowing what I want to know.”

***Watching you watching me- we are both afraid.***

The experience of living with a cloud overhead was made further complex when the impact on the study participant’s social network was considered. One participant spoke about the times she would observe her family looking at her and stated “You know it’s like sometimes I’d catch them, and they’d look at me like you know... and I’m thinking... ‘I’m not dead.’”

Several participants realized that the reactions of others were rooted in their own fears of death.

For example, one participant stated,

I can give you some interesting anecdotes. Um, my son’s girlfriend—I’ve, I’ve learned that people, when people encounter people with cancer they start processing their... their own mortality... They’re processing their own mortality and they, um... My son’s girlfriend wouldn’t let him microwave food...because she was afraid they would get cancer. Everything, suddenly everything was about them getting cancer. Okay and then all this talk was then, you know about them, them and the cancer and them, and they might have... And suddenly they were going for all this testing and all. And I’m sitting there thinking (pause) I’m the one with the cancer. [Laughs]

Women experienced intensified distress related to seeing the impact on those they loved and one participant noted that the “hardest part is the pain this causes those I love.” They are sometimes caught between what they need and what those around them need. One participant who acknowledged needing support but was unable to share information with her family related,

Yeah, so I just had the CAT scan on Thursday and its showing, a, you know, regression of the...of the spots, so... So now I'm... I mean I feel better ... But it... But when she first told me about the spots, I laid in my bed for a week and just said, "That's it," you know? I mean the fear and the knowledge that... It's just a horrible feeling, that fear that you like - ...- there's something. It's back. It's coming back, so... And...And I hadn't... I didn't tell my... I didn't even tell my husband when the numbers were creeping up ...and even that I was having the CAT scan because I didn't want to put them through more of everything, so I've dealt with it myself... and it just... I didn't want them to...they'd already been through so much, I didn't want to upset the...upset them with more bad news and I didn't...I was afraid to tell them.

Study participants don't want to feel pity from others. One participant described her need to limit interactions with others and had learned that "a smile hides much." She was able to continue her work responsibilities by not sharing her personal experiences.

An identified theme or property which supported this subcategory was in regards to the awareness that "...some of this I have to do by myself...some of this we have to do together." Reactions of others helped participants to know how much they could share as noted by one who stated, "...sometimes how you respond makes it harder for me." It was necessary at times to withhold information to protect others from worrying. Having to deal with other's fears and expectations lead to the participant's awareness, i.e., "this is about me, but sometimes it becomes about you."

Relationships were acknowledged as complex. Each participant identified trusted individuals who were able to be flexible and respond with support and who could tolerate honest emotions. These were not always family members. Healthcare providers who were able to listen and “treated the patient, not the cancer” gained the trust of one participant.

In this study sample, participant contact with other women with ovarian cancer was limited for a variety of reasons. One participant mused that “It might be nice to talk to someone who has gone through this,” but described herself as a very private person and not likely to attend a meeting. One participant who identified herself as actively engaged with an internet chat site observed that “almost every day someone dies on those bulletin boards, you know. ‘So-and-so earned her wings’ ... It happens almost every single day.” She noted that it was difficult to be confronted with death so frequently. Another participant preferred not to attend a support group, because she needed to focus her attention on her own survival issues and was not able to provide support to others. The complexity of relationships was further illustrated with the theme about “talking yet not talking, about death” and was strongly influenced by the response of the other individual.

***Talking yet not talking, about death.***

This theme was observed sometimes in what was not said, in the voice changes, the hesitations, and the struggle to find the right words. It reflects the earlier subcategory of “knowing what I don’t want to know and not knowing what I want to know.” However, for the earlier subcategory, the emphasis was on the internal processing of the realities of living with a new and unwelcome normal, or even living with the poor prognosis and the expectation of an early death. The subcategory of “talking yet not talking, about death” was recognition of the

social communication where those uncertainties were cautiously both spoken and unspoken as exemplified by a participant stating, “I’m going to... you know....This is it.”

All participants related past experiences with death, whether their own, or close family members. Several had “almost died” during the pre-diagnosis or treatment phase. Two had lost their own mothers to cancer (one at age six and one at age 21), while others had lost close family members. They acknowledged the statistical prognosis, with one saying that she knew she had a “50/50 chance.” Demonstrating a preference to avoid conversations about death, one participant, referring to internet chat sites, noted “When women are talking about things like that I go to another subject because it doesn’t apply to me.” However, this same participant shared freely the story of her sister’s recent death and her own personal measures to find treatments despite being told by physicians that there were not more treatments available, stating,

And a lot of women don’t know how to express themselves or don’t think it’s worth it because nothing’s going to get done anyhow because they know that, you know, once you can be considered you have a death sentence, they won’t look for other things for you. You have to be your own advocate here...you have to look for other things. Had I not looked for other alternatives...the surgery that I need...or the, um, the chemo...the trial that I’m going to qualify for....you have to go elsewhere.

Thus, this participant both avoided and confronted the topic of her own death. This avoidance and confrontation was demonstrated by all participants and talked about in regards to their family and friends. One participant related an exchange with a family member,

Somebody said something to me that was really hurtful- was my sister-in-law, who I do like a lot, but we were talking about vacations and trying to schedule time because I want

to spend time with my niece and my nephew. And of course when I was first recurred you know...my life expectancy then was like nine months and so I was like “Crap, I...we need to like”...and uh...we were talking about vacations and she goes “Why can’t we just be normal”(pause). And you know, I thought about that a lot. I’m like “Because things aren’t normal.” You know...I can say I want to have a day where I don’t think about cancer, but to pretend like things are normal, things will ever be normal, I don’t think so. So I guess I would say to people to recognize that this is my reality.

The ability to talk about death depended upon both the personal internal readiness of the participant and also upon the response and readiness of those around her. This created a complex dynamic because ultimately every conversation post-diagnosis is within the context of being diagnosed with and treated for ovarian cancer. One participant reflected on how to balance the need to talk about it or not, as it was illustrated in her relationship with her boyfriend and making decisions,

...and so all of your decisions, unless I don’t know, maybe some people are really good at, maybe they just made a decision that they’re going to live like they are going to live. Like I bought a house this year...so that was a decision that was living like I’m going to live. I just bought a rental house as an investment property, so that’s a decision about living like I want to live... so I’ve been making my decisions like I’m going to live. But maybe some people have decided you know...the odds are I’m not going to live more than four years ...so I’m going to live like I’m going to live four years. And that would be a reasonable thing to do. It’s scary to me but reasonable. So- but maybe if you make that decision upfront, “This is how I’m going to do it,” you don’t have to think about it



over and over again every time you have to make a new decision. You can alleviate that thought process, but...I had to hand him death again. [referring to a conversation with her boyfriend about a major purchase]...Every time I discuss it I have to hand him death again....And so I'm stuck between do I not share... or do I hand him death again....It's a big responsibility...(pause). There are some people around you that can't go there. ...they can't, you can't have a real conversation with them about dying, about the path there and what you're afraid of and what you're okay with and how you want...they just can't. They're not ready, they're not there...and I think it's helpful for patients to sort of understand that some people can and some people can't...and see, in their minds kind of know... who's who.

The readiness of others to approach difficult conversations impacted the intimacy of relationships. Family members or friends who were not able to adjust to the new reality were sometimes relegated to a more distant social position. These persons were often identified as actually adding to the measure of stress or distress that the participants experienced. Participants found it easier to minimize contact with those individuals. The uncertainty of the diagnosis and treatment made conversations difficult. The participants expressed the paradox of knowing, yet not knowing, so there were times when they were ready for more concrete conversations and sometimes when they were not ready. Family members also experienced the uncertainty, and were not always able to manage their own emotions. The overall preference was to “hang on to hope” with a degree of fear that if they talked about death, that it made it more real.

Healthcare provider's conversations were also included in the participant's comments that reflected this theme. Participants wanted to be told the truth, but also needed to have hope.

One participant chose to seek a second opinion when she felt the physician “had given up on me.” Another participant reflected on the dilemma faced by physicians,

... I know doctors don't want to give people false hope because that's just as bad... and I don't know how you balance that with, you know, is it better to know that there's...okay, you have three months to to live and deal with that, um, or give people, you know, hope and say, “We're not sure. We don't know.” I don't know which is worse, to say, “I don't know,” or say, “Okay, this is what you have.

For all participants, the focus was on hope and pursuing treatments that would lead to remission.

One participant, who was close to the five-year survival date and had just learned of her recurrence, said with emphasis “I don't allow anyone to take my hope.” Her determination to avoid any “negativity” was reflected in her statement,

But you just give people grace because they don't know what to say and they... they're nervous about it. I'm not nervous about it...they're nervous about it. My family can get nervous about it...so they say things and ask me things and I'll say “Today I'm whole, so let's live in the day...Today I'm whole. Today I'm well.” Today I'm well. Today I'm well. Today I'm whole. Let's live today, you know. But we do have um...my daughter and myself, you know when we ride in the car now, which we didn't do before, we just hold hands....You know, so I'm okay with that, but today I'm whole; I'm well.

Other participants chose to put their lives in perspective and reflected “I've had a good life” and “everyone has to die someday.”

*Now I have to take care of me.*

Over time, the participants discovered the need to focus on self-care. Speaking about attending a support group, one participant explained her decision not to attend by stating “This is the time for **me**, and I can’t be **me** if I’m a part of **we**.” Reflecting on the changes in her life, another participant noted that “I took better care of others but now I am taking care of myself.” And another verbalized “...so I would spend... I believe I would spend more time taking care of them to get them over what I’m going through than me, and **I want to be focused on me**, (fingers pound on table).” Coming to the realization that “now I have to take care of me” was a source of tension and of discomfort because many of these participants had been in the caretaker role and responsible for maintaining connections within the family. Often no one else was prepared to assume those informal duties. However, in this instance, changes were needed and those relationships which did not contribute positively were minimized or even eliminated. Quality of life and preserving personal dignity was an important consideration and expressed well by one participant.

So then we go back to weighing quality of life versus longevity...because to live 80 years but not have quality of life doesn’t really matter... to me. to me. and you know I’ve seen patients who I just think, “Why won’t the family give them permission to go? They’re holding on for the family. Why won’t the family give them permission to go?” **They are suffering. Suffering.** And I could see my family doing that. Do...do...anything you need to do to keep her alive. No, that’s why I have advanced directive. My advanced directive says, “Don’t you dare do everything to keep me alive. If I don’t have quality of life, (pause) let me go.”

The new focus on self was demonstrated in a variety of ways. Reducing stress and choosing healthy alternatives was an important strategy for participants to take care of themselves. Two of the participants referred to themselves as the mythical phoenix and one expressed plans to get a teal-colored phoenix tattoo. Having future plans, improving nutrition, and getting a massage were mentioned as self-care activities. The internet provided options which several explored, particularly as the success of traditional medical intervention waned. Clinical trials offered hope and provided the opportunity to help someone else if they did not personally benefit. Participants employed a variety of methods for taking care of themselves. One participant stressed “It is important for you to know your doctor and for your doctor to know you” and she had changed physicians to find one who contributed positively to her emotional as well as physical well-being.

Each participant mentioned prayer or mediation even if religion was not part of their value system. One stated,

Um...What do they say “There’s no atheists in foxholes.”...I’m surprised that there are any ah um...atheists in cancer. And I don’t know that they go to god, you know, depending on where you are beforehand. And I have not been a religious person in a long, long, long time and you know I started out from a place of um....agnosticism, like I have no idea. You know, I don’t.....I don’t have the hubris to pretend to know...what’s going on out there. But there are definitely some moments where you might shoot a prayer out to whoever, whatever, however and make the deals that you make. Um, I you know, think that in doing yoga...you know, you have those moments on the mat where they...somebody says something about living in the moment that I find particularly...um

particularly meaningful...and so to the extent that working on living in this moment right now and the spirituality that's attached to that idea...for me that runs pretty strong.

This new focus on self was beneficial as participants needed to advocate for themselves and pursue additional, even experimental treatments. However, the participants also experienced a sense of isolation and aloneness following the diagnosis of and treatment for ovarian cancer. The dream that one participant related summarized the aloneness, in the midst of relationships, that she experienced and helped explain what the experience was like.

I'm sitting on the beach and I'm reading a book...I am the only person on the beach...I put my book down and I walk up to the edge of the waves...I get far enough out that I can lay on my back and float...the ocean is just rocking me...after a little while I decide to turn around and tread water...I look back at the beach and where it had been unpopulated...everybody I've ever known my whole life is on the beach...Then the scary part happens. There's a fin...another fin...the fins start circling around me...I start waving my arms...at all the people on the beach...[they] just smile and wave back at me...and of course the fins are circling and so I wave more frantically, the sharks are circling...death is circling...they don't get it...then I wake up in a cold sweat...And that's what it feels like to have cancer...everybody is that close...going on with their lives...they can't know what it feels like because they're on the beach and it's not happening to them.

## Conceptual Model

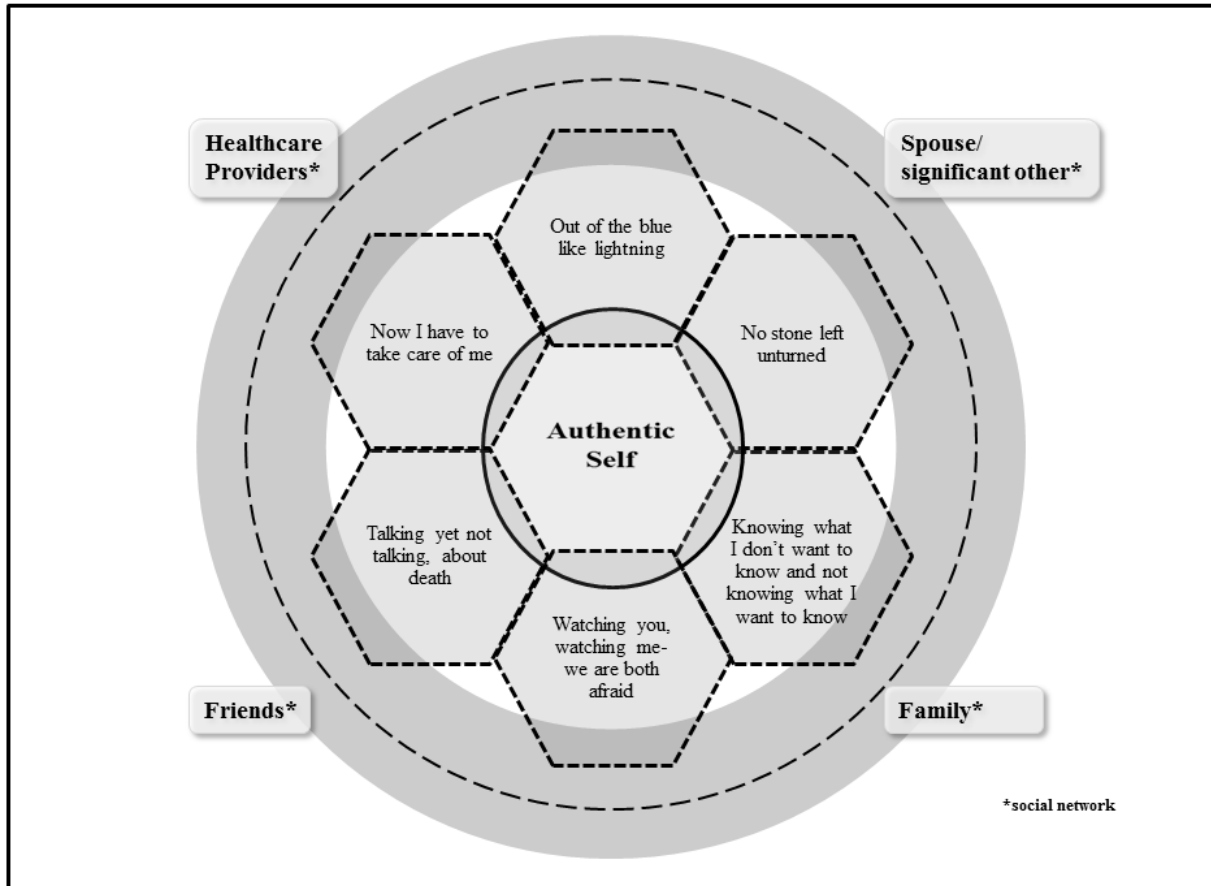


Figure1: Ovarian Cancer: Existential Assault

The conceptual model that resulted from this grounded theory study is multifactorial and dynamic, not linear or static and begins with the diagnosis of ovarian cancer for a woman. The nursing phenomenon of concern is the experience of distress for 12 women diagnosed with and treated for this disease. The research question evolved from the author's experience as a surgical oncology nurse. The study was motivated by the observation that women had unmet needs in relation to their experience of distress when diagnosed with and treated for ovarian cancer.

Participants agreed to answer the research question: "What do women with ovarian cancer want

their spouse/significant other, family, friends, and healthcare providers to know about their experience of distress during diagnosis and treatment?”

The experiences of the participants diagnosed with and treated for ovarian cancer contributed substantive data and led to the emergence of a substantive theory of “Existential Assault.” The six subcategories represent the abstraction and conceptualization of interview content for this study. The core variable of this conceptual or theoretical model is “existential assault,” which accounts for how the participants responded to the perceived threats to existence inherent in the diagnosis of, and treatment for, ovarian cancer. The participants experienced this phenomenon at both a personal level and at a relational level. The diagnosis and treatment altered each participant’s future. It also altered her relationships with her social network, i.e., spouse/significant other, family, friends, and healthcare providers. These alterations and the relationships among the six subcategories appear to be dynamic rather than static. They are interrelated and do not stand in isolation of one another but combine to lead to the emergence of the authentic self. From the initial unexpected diagnosis experienced as “out of the blue like lightning,” the participants and those around them looked for cure or remission seeking second, third, or fourth opinions as evidenced by “no stone left unturned.” The participants expressed “knowing what I don’t want to know, and not knowing what I want to know” when they talked about the poor prognostic outcomes, their hope for remission, and the loss of living a normal life. Relationships with others quickly became differentiated as close or distant, depending upon the ability of others to process the realities of the participant’s experience and their ability to respond. Cues were both given and received as “watching you watching me- we are both afraid.” Important conversations occurred in response to the ability of each person to accept the

implications of both the diagnosis and the treatment and there was a presence of “talking yet not talking, about death.” Participants expressed the realization that “now I have to take care of me,” which evolved in the midst of the experience. In a concept analysis of the variable, authenticity, Starr (2008) determined that the defining attributes included the process of self-discovery, realizing and acting on personal potential, and accepting the responsibility for life choices. While the diagnosis of ovarian cancer was not a voluntary life choice, these study participants did demonstrate an assumption of responsibility for choices thrust upon them by the diagnosis. In doing this they seemed to reach a place of self-discovery, realizing and acting on their personal potential as reflected within the six subcategories. Therefore, the self who emerged because of living with and responding to the diagnosis of, and treatment for, ovarian cancer contributed to the emergence of an “authentic self.”

The subcategories and the relationships between and among the elements of the conceptual model are represented in Figure 1. The center circle represents the woman and the resultant authentic self who was personally responsible for life choices and determining meaning and purpose for her life. The surrounding hexagonal shapes represent the identified six subcategories which contributed to the “existential assault.” The six subcategories overlap the middle circle, suggesting that they influence and are influenced by the authentic self. The lines are broken to note the fluidity of the nonlinear, multifactorial process. The psychosocial interactions of the model, i.e., the interrelationships among and between the individuals of the social network and the study participant, are visually demonstrated by the outer circle which overlaps the six subcategories. The overlap represents the bidirectional influence that the subcategories had on the relationships among the authentic self and those in the social network



and the influence that others, and the authentic self, had on the subcategories. The outer circle is open to represent that the relationships of those within the social network were peripheral and moved between close and distant positions. Movement depended upon the ability of others to manage their own emotions when in relationship to the participant diagnosed with and treated for ovarian cancer and as she assumed the identity of her authentic self. Those individuals who compounded the experience of distress were relegated to a more distant position, depending upon the decisions made by the authentic self. The interactions of the different elements of the model provide a pictorial representation of what women diagnosed with and treated for ovarian cancer experienced as distress in the form of an existential assault and thus help to answer the research question “what do women with ovarian cancer want their spouse/significant other, family, friends, and healthcare providers to know about their experience of distress during diagnosis and treatment?”

### **Propositional Statements Supporting Model**

Propositions help to provide narrative understanding of the elements of a conceptual model. Fawcett (2005) defined the term, proposition, as a “...statement of the relation between two or more concepts” (p. 4). The elements of this conceptual model have been presented. When examining the inter-relationships among the authentic self, the six subcategories, and the social network, descriptive statements that explain the model as developed through study findings may include, but are not limited to, the following propositions: (a) receiving a diagnosis of ovarian cancer is an unexpected event that does not exist in isolation because the woman is impacted in all aspects of her life; (b) the six subcategories do not exist independently of one another but inter-relate with each other to impact the development of an authentic self; and, (c) the response

of the participant, i.e., the authentic self, to others in her life is influenced by their experience of the six subcategories and their ability to manage their own emotions regarding her diagnosis of and treatment for ovarian cancer. While these propositions are not all inclusive of the relationships within the model, they suggest the potential for the development of a theoretical framework that may guide nursing interventions for distress management and improved support mechanisms for women diagnosed with ovarian cancer. This is not the final word but the beginning of an exploration to improve the quality of life in these women by addressing what women want others to know about their experience of distress because of this diagnosis and subsequent treatment.

## CHAPTER FIVE DISCUSSION

### Introduction

This study was a qualitative inquiry, using grounded theory methodology of Glaser and Strauss (1967) further clarified by Glaser (1965, 1978, 1992, 2008, 2012), asking the research question :“What do women with ovarian cancer want others (spouse/significant other, family, friends, and healthcare providers) to know about their experience of distress during diagnosis and treatment?” A review of the literature revealed that distress has been inconsistently defined and measured, making it difficult to draw conclusions from research studies. Distress was most often considered as anxiety or depression, but there were a wide variety of terms and measures used. Several researchers have concluded that women with ovarian cancer experience distress (Cain et al. 1983, Dawson 1993, Portenoy et al. 1994a, 1994b, Norton et al. 2004, 2005, Lobchuk & Bokhari 2008, Matulonis et al. 2008). The four broad categories identified in the literature by the investigator were psychological distress, psychosocial distress, spiritual distress, and physiological distress. Additionally, ethnographic studies and a variety of qualitative studies have reported women’s perspectives related to cancer diagnoses (Fitch et al. 2002, Ferrell et al. 2003a, 2003b, Ferrell et al. 2005, Reb 2007, Power et al. 2008, Ponto et al. 2010, Schulman-Green et al. 2012); however to date, women have not been asked what they would like others to know about their experience of distress.

### Discussion of Study Results

Twelve participants provided rich, candid details of their diagnosis and treatment as well as the emotional impact on themselves and those around them. This provided the perspective of

those with the lived experience regarding distress associated with the diagnosis of and treatment for ovarian cancer. For these participants, the diagnosis was not only unexpected, but receiving this diagnosis forced them to face their mortality, while also managing and maintaining their lives, lifestyle, and relationships. The 12 audiotaped interviews provided data for analysis using the constant comparative method. Through abstraction and conceptualization of the data, the theory of “existential assault” emerged and a conceptual model was developed. The term “existential assault” captures the new reality that participants confronted on a daily basis. The six subcategories were grounded in the data and reflected how the participant and her relationship with her social network was impacted by the “existential assault” as well as how new responses were required in order to fight the disease and cope with the new realities imposed by the diagnosis. That is, the participant found it beneficial to adopt coping strategies which impacted existing relationships in order for her to manage her own distress. The conceptual model (Figure 1) that has emerged from this study’s grounded theory method has the potential to improve understanding of the experience of women who receive a diagnosis of, and treatment for, ovarian cancer as well as for those in her social network.

### **Existential assault.**

In what may be considered a “seminal” article, regarding the existential experience of cancer diagnosis, Weisman and Worden (1976) found that the first 100 days, compared with the second 100 days, were the most vulnerable for patients as it “related to existential problems” (p. 10). In a longitudinal study that included men and women ( $N=120$ ) with a variety of cancer diagnoses, the authors tested for coping strategies, resolution of problems, vulnerability, total mood disturbance, and predominant concerns. The authors reported that patients with advanced

lung cancer ( $n=23$ , all men for this study) demonstrated the highest levels of distress and most vulnerability. Weisman and Worden (1976) concluded that the “correlation is consistent with the high mortality rate, [and] poor therapeutic response” (p. 9). In the current study, participants were not evaluated with any such measures; however, the abstraction and conceptualization of the substantive data revealed that existential issues were central to their experience. Using a phenomenological study design, Laranjeira, Leão, and Leal (2013) examined existential concerns for survivors of “female cancer” in a sample of Portuguese women ( $N=10$ ). The authors found that women had the opportunity to “define an authentic self-identity” (p. 136) and that the participant experience included self-discovery, learning how to exist in the world, and how to communicate with others. The themes identified by Laranjeira et al. (2013) were reflected in the findings of the current study.

A proposition from the current study is that the relationships between the six subcategories were dynamic and not linear, with each component influencing and being influenced by each of the other components. The impact of the existential assault changed life plans and relationships for the participants as well for the participant’s own self-perception. The participant discovered or learned new ways of relating to those in her social network as she assumed responsibility for her own decisions and life choices.

### ***Out of the blue like lightning.***

Participants from this study related that hearing the diagnosis of ovarian cancer, even if they had been experiencing symptoms, was unexpected and came “out of the blue like lightning.” Similarly, Reb (2007), also reported “unexpected shock” in a sample of women ( $N=20$ ) diagnosed with advanced ovarian cancer. Contributing to the shock of the experience for

the current study participants was how their initial concerns were incorrectly diagnosed or dismissed. Even those participants who knew “something was wrong” found the diagnosis of ovarian cancer to be shocking. Several related that there was a time lapse for when they were able to understand the implications of the diagnosis, with one stating “it didn’t register so she repeated it.” Ferrell et al. (2003a) reported that one participant related “prior to being diagnosed, I went to numerous doctors for a whole year complaining of symptoms that I now know was obvious for ovarian cancer. The doctors kept telling me it was menopausal or stress related!!” (p. 532). Fitch et al. (2003) found that participants in their study were overwhelmed with feelings of shock and fear when given the diagnosis (p. 9).

The method in which the actual diagnosis of ovarian cancer was delivered contributed to the shock, with two participant’s reports of having been informed of the diagnosis over the phone. Cain et al. (1983) investigated the psychosocial impact on women diagnosed with a gynecological malignancy ( $N = 60$ , with 25% ovarian cancer). The 25% of participants who were informed by telephone described the experience as “frightening” (p. 637). While the urgency for treatment may have influenced the circumstances in which the study participants in the current study learned of their ovarian cancer diagnosis, news of this magnitude would be best delivered in person with support readily available. Though participants in the study had different experiences, conceptually, all expressed shock when the diagnosis of ovarian cancer was presented.

In the current study, non-verbal cues such as body language, avoiding eye contact, and uncharacteristically urgent testing and referrals were other ways in which study participants were informed of the seriousness of the medical findings. Fitch, Deane, Howell, and Gray (2002)

reported that the participants with ovarian cancer in their study ( $N=18$ ) related that communication with healthcare professionals was “confusing and difficult” (p. 156). In summarizing the participant comments, Fitch et al. (2002) stated, “. . .they expressed disappointment with health professional’s behaviors in that they felt some . . .were hesitant and not forthright with information about the diagnosis” (p. 156).

It is proposed that the unexpected news of an ovarian cancer diagnosis related to and impacted each of the subcategories as well as the participant and her relationships with her social network. This news was the catalyst that triggered the “no stone left unturned” response, required internal and external processing by the participant and her social network, and imposed changes in relationships, both with herself, and with others. Additional needed research highlighted by the results of this study and supported by the literature includes examining ways in which to improve patient support when given the diagnosis, by exploring (a) the optimum manner for delivering a difficult diagnosis, (b) how to help patients process difficult news, (c) how to help prevent delays in diagnosis, (d) how to develop an increased awareness of non-verbal cues that patients may interpret correctly or incorrectly, and (e) how to create an environment where patients are able to ask questions and express fears. Physicians are generally responsible for giving diagnoses; however, nurses are often present when the diagnosis is given, and are frequently the provider for follow-up care. While the current study sample was small ( $N=12$ ), and generalizations cannot be made on the basis of this study alone, the existing literature supports the need for nursing research to examine improved ways to support this patient population. Additionally, these findings support an argument for developing nursing

interventions that include advocating for patients who are receiving difficult diagnoses and subsequent interventions to assist them with asking questions and gaining information.

*No stone left unturned.*

After receiving a diagnosis of ovarian cancer, these 12 participants and their social networks turned to identifying the best physician and the best treatment to ensure remission, if not cure, and to “improve my chances.” This focus reflected the awareness that this was potentially a “life and death” matter. Several study participants reported being willing to seek as many “second” opinions as they could find and were equally willing to travel to other cancer centers in search of all available options. The physician’s competence and compassion were both of concern though one participant suggested her preference for competence from the physician with compassion provided by other staff. For some, participating in clinical trials was another positive action and helped them feel that they were doing everything within their power to fight the disease. When participants did not feel comfortable with their physician’s approach, or the treatment available, they changed to another practice or practitioner. One participant clearly stated “I’m not sticking with one hospital or one doctor” in her effort to find all available treatment options.

Gill and Whisnant (2012), using a grounded theory study design, found that on an internet site, participants with ovarian cancer ( $N=93$ ) were classified as “information providers” or “information seekers” (p. 54). The authors found that the online conversation provided an opportunity for women to compare treatment strategies and to find alternative types of treatments. Bowes, Tamlyn, and Butler (2001), also using a grounded theory study design in women with ovarian cancer ( $N=9$ ), noted that study participants took “action strategies” in



relation to the “cure, prognosis, and treatment of ovarian cancer, in addition to answers to [and asking] questions that they knew in their heart could not be answered” (p. 142). Getting additional information from a variety of sources contributed to having a sense of control in managing their diagnosis and treatment.

Power et al. (2008) and Reb (2007) found evidence that some women developed action plans and strategies for fighting their cancer, but they also found evidence of the opposite response when women chose avoidance. In both studies, a grounded theory design was used in samples of women diagnosed with ovarian cancer. Power et al. (2008), examined psychosocial distress, coping and social support and focused on coping strategies and communication patterns ( $N=30$ ). While they found some women who actively sought information to the point of becoming “experts” on ovarian cancer and their own health, they also described coping mechanisms, used by some, as “avoiding and blunting” (p. 375). In the latter case, women used distraction, optimism, denial and even humor to manage the level of stress that they experienced in regards to the diagnosis and treatment. Reb (2007) reported study participants ( $N=20$ ) as having used contradictory coping mechanisms of seeking versus avoiding information. That is, some women sought control over their diagnosis by seeking information outside of the physician’s care, actively preparing for treatment and familiarizing themselves on all aspects related to ovarian cancer treatment. Other study participants, however, preferred not to know anything other than what their physicians told them. The review of the literature demonstrated that there were a variety of responses for women who receive a diagnosis of ovarian cancer with some seeking additional information, and some preferring to rely on their physician for information.

Lifestyle changes for the current study participants included measures to control their personal stress levels, such as surrounding themselves with positive influences and eliminating negative influences. For some, this involved drastic changes such as quitting their job and even eliminating some relationships. Participants also explored alternative treatments which included Complementary and Alternative Treatments (CAM), as well as simple lifestyle changes. Finding the best physician and the best treatments, choosing to participate in clinical trials, seeking additional information or becoming “expert”, and experimenting with alternative treatments were all means of women creating personal action plans or strategies in an effort to increase their survival chances.

Once again addressing the limitation of this study’s small sample size and therefore study findings not being generalizable, the review of the literature supported the study findings. Therefore, the investigator suggests that research on the topic of supporting women in their efforts to become self-advocates and to manage or control their own experience may be beneficial to their overall quality of life during an intensely stressful time. However, dealing with a diagnosis and treatment for ovarian cancer can be a complex issue, meaning that it is important to identify personal preferences in every case. Women who prefer not to actively create or pursue their own personal action plans may need different support measures.

Further reflecting the subcategory of “no stone left unturned,” one study participant suggested that a center dedicated to ovarian cancer would help promote research and make the latest information available. For her, this would include exploring the effectiveness of alternative treatments and in how to evaluate unproven treatments for potential harm. While information about clinical trials may be helpful to some patients, one participant found the number of

available trials to be daunting without the medical knowledge to be able to evaluate which ones would be a good match. In this light, nurses are poised to help patients find reliable sources of information and evaluate alternatives through the advancement of nursing science.

Participants in the current study demonstrated a wide range of responses, but the predominant theme was one of exhausting all options in an effort to improve their survival chances. The comparative lack of information, resources, and media attention for ovarian cancer created concern for some that they were getting the best information and latest treatments available. This theme was also supported in the literature. Ferrell, Smith, Ervin, et al. (2003) identified a written comment in their ethnographic review, “With all the public awareness of breast cancer I feel like ovarian cancer is the poor relation, with survivors left to fend for themselves in regards to medical research and public outreach” (p. 654). Increasing public awareness of the disease and helping to remove the stigma of having cancer in general, and more specifically a “female cancer” is also within the realm of nursing influence. A proposition for the relationships for the subcategories related to “leaving no stone unturned” include the participant’s creation of an action plan to fight the disease and its “existential assault” and the participant’s need to learn new means of self-advocacy and self-management. However, as stated previously, each of the subcategories and the participant and her social network are interrelated in bidirectional and non-linear directions.

***Knowing what I don’t want to know and not knowing what I want to know.***

In the current study, participants would frequently hesitate, pause, or search for the right word, when speaking about outcomes related to the diagnosis. Some wondered at times if they were being given accurate information or “the truth.” The implications for their future made it

difficult to make decisions when considering how to spend their time and their money. The uncertainties of treatment introduced both hope and fear since the outcomes may be favorable or not, which one participant summed up as “never knowing if you are going to get better or worse.” Recurrence was an ever present reality. In general, participants knew the unfavorable statistics of their diagnosis, but did not know how that would impact their life. Illustrating the theme of “knowing what I don’t want to know and not knowing what I want to know,” one participant gathered her own information in addition to that given to her by her physician. She articulated a holistic and comprehensive personal action plan. However, she reported making one visit to a support group and discovered that while she wanted information, she found that she did not want to know the information shared within the group setting and never returned. Similarly, Power et al. (2008) reported a participant stating, “I went to the internet for things, but then I found things that I didn’t want to know, so I stopped doing that” (p. 372). In a study by Cesario, Nelson, Broxson and Cesario (2010) with ovarian cancer patients ( $N = 360$ ) representing young, middle, and older adults, participants identified *recurrence* as among their primary “worries” (p. 610). The participants from this study expressed hope for remission, but were also aware that long term ovarian cancer survivors are not common, raising concern for their own personal survival. Though the specific incidents differed, participants of the current study related that there was information that they knew but didn’t want to know. There was also information that they wanted to know but the answers were not available to them.

Propositional relationships in the study findings included this subcategory and how it related to the others. Participants and their social network both exhibited an inability to process difficult information about the disease. This was seen as, at times, knowing unwelcome “facts”

but choosing not to acknowledge them and at other times as fear of an uncertain future.

Participants in the current study lived with the reality of the poor prognosis of ovarian cancer experienced at times as a “cloud hanging overhead” and struggled with the question “Do I live like I’m going to live or like I’m going to die?” Choosing to avoid negative thoughts and information was one way some chose to decrease stress, though some also chose to find out all that was available in order to give themselves the best options. Controlling the amount of information available to them was part of the effort of participants to adjust to the new reality of living with a diagnosis of ovarian cancer. Research studies to identify ways to support women who are processing the uncertainties of the diagnosis of ovarian cancer would be helpful. Additional research into coping mechanisms and the role of hope and fear could potentially provide evidence for anticipatory guidance in women facing the uncertainties of ovarian cancer.

Nurses have opportunities to assess the needs of women diagnosed with and treated for ovarian cancer. Participants in this study reported feeling ambivalent at times in their need for information. Nurses can offer the opportunity for asking questions in a safe environment and guide women toward reliable sources of information and referral for additional support as needed. One participant in the current study spoke highly of the contribution of nurses and her perception that nurses were there to “make sure that you are okay.”

***Watching you watching me- we are both afraid.***

All participants were concerned for those around them and found it hard to watch others suffer because of their illness. The impact the diagnosis had on others led to participants reporting that they withheld information in order to prevent bringing pain to or increasing fear for their loved ones. Even those with positive, supportive relationships found it necessary to

gauge their conversations based on the ability of those around them to respond. Not only were they dealing with their own fears and questions, they were also dealing with the fears and questions of those around them. “They can’t do anything about it anyway, and then I would have to take care of them” was the way one participant explained her preference for not sharing information with her husband and children about her advanced and recurrent cancer. Women’s concern for their family members was a common theme in the literature as well (Reb, 2007, Halstead & Hull, 2001, Bowes et al., 2002). Some studies have explored the needs of caregivers in addition to the patient (Frost et al. 2012, Morris, 2007, Butow et al. 2014).

The psychosocial dynamics of relationships was noted to be complex and one participant observed “this is about me, but sometimes it becomes about you.” Participants and their social network took cues from each other regarding how to respond to the diagnosis of and treatment for ovarian cancer. This emphasis was a bit different than the focus of the literature on the support needs of women with ovarian cancer as discussed in studies by Ferrell, Smith, Ervin, et al. (2003), Akyüz et al. (2008), Manne et al. (2008), and Power et al. (2008). The general concern in the literature was in regards to the available support system and its impact on quality of life, with some effort to identify the caregiver’s needs. While the impact of the illness on others has been identified, the intensified experience of distress for women imposed when those in her social network struggle with the meaning for themselves, was not identified in the review of the literature. Research to benefit women with ovarian cancer could also consider the impact on women when they must provide support for their own social network, that is, when they end up supporting the persons who are their support system. Women’s experience is impacted by the experience of those around them. It is important, as Lobchuk and Bokhari (2008) concluded,

that healthcare professionals pay “greater attention to the interpersonal rather than the individualistic processes of stress and coping in patients” (p. 813).

While the sample size of 12 participants limited the ability to suggest generalizable nursing implications, there is literature support for exploring ways to enhance the psychosocial support for both the individual with the disease and caregivers. The propositions for the relationships for this subcategory include the impact that the participant has on her social network as well as the impact that others have on her experience of distress.

***Talking yet not talking, about death.***

The ability to share information was dependent upon the ability of others to receive it, and this was especially noted in conversations that suggested death. One participant had already planned her own funeral, which was “by invitation only.” Her funeral arrangements were discussed with five identified close friends and did not include her family in the planning. During the interview, she quickly changed the subject to her personal action plan for finding the best physicians and treatments, demonstrating her own tenuous ability to talk about her own death. Bowes et al. (2001) noted that some women chose not to talk with their families, with the thought of not wanting to burden them. Others were aware that friends would become “tired of talking about such a serious issue and might begin to avoid them” (p. 142). Participants in the current study related that they had learned communication strategies for talking with others as it related to their diagnosis. Some of the strategies were self- and other- protective in that neither the study participant nor others were ready to engage in uncomfortable conversations.

For some participants, there were relationships that became irrelevant to them and thus, those individuals were excluded from significant conversation beyond social pleasantries. One

participant chose to say “I’m hanging in there” in response to the ever present question, “how are you?” She related that this allowed for the depth of the encounter to be controlled by the person asking the question. For those whose family or friends needed or wanted to be part of the diagnosis and treatment process, there were varying levels of acceptance and readiness to engage in significant conversations. For example, participants would gauge whether or not to share or withhold information at each encounter. Participants were able to identify relationships where it was safe to explore existential issues regarding death and those where it was not.

Another strategy for dealing with the topic of “talking yet not talking, about death” was the use of humor. One participant, in particular, noted that she felt that her humorous approach to the diagnosis and treatment of ovarian cancer helped to relieve her stress as well as to prolong her life. Rose, Spencer, and Rausch (2013) used an interview guide to explore the use of humor in coping with the diagnosis and treatment in women ( $N=17$ ) diagnosed with recurrent ovarian cancer. The authors suggested that humor allowed patients to alleviate anxiety and avoid denial while “psychologically shielding themselves from the untoward psychological consequences of their diagnosis and mortality” (p. 778). Bowes et al. (2001) also noted that humor was used as a coping mechanism. Ferrell et al. (2003b) included a participant quote reflecting the use of humor during treatment.

For chemo in the hospital, I wore funny glasses with the eyeballs falling down, and I put on large rubber ears. Great compliments to my bald head. I got lots of attention from the staff plus from other patients. We had some good laughs. My doctor calmly told his nurse ‘that’s what happens when a patient gets too much chemo’ (p. 1065).



In the current study, humor appeared to be another way to address “talking yet not talking, about death.” Voice changes, pauses, and hesitations demonstrated that the topic was too emotionally charged to talk about at times. Participants in the study learned ways to determine if and when conversation about serious issues was acceptable or not.

A propositional relationship for this subcategory could include the statement that difficulty in talking about death is a barrier to study participants feeling supported. Conversations depended upon the ability and readiness of each person to engage in real communication or the need to maintain a degree of personal comfort. Nursing research opportunities include exploring ways that women communicate their readiness to talk about serious issues. The readiness of those individuals who are their support system is also an important aspect of patient and family care. It may be that such individual’s needs are different than those of the women themselves. Nursing implications include providing safe opportunities for patients to explore difficult topics and providing resources for reliable information.

***Now I have to take care of me.***

In response to the perceived existential assault, study participants expressed a realization that they, themselves, needed to be responsible for choices in a way that brought them a sense of meaning and purpose to their life. They made statements such as, “Now I need to take care of me” and “[I am] changing my focus from others to myself.” This movement towards self-advocacy and self-management was reflected in some participants making a “personal action plan” that included practicing regular stress management techniques, getting massages, and managing their home lives in a fashion that better supported their health and well-being. The research literature supports this study finding. For example, in a descriptive qualitative study

using focus groups, Hagan and Donovan (2013) proposed that self-advocacy was an important concept for women with ovarian cancer ( $N=13$ ). In their study, self-advocacy was illustrated by a participant who “negotiated a treatment plan with her oncologist that fit her needs” and also by a participant who was able to “put her symptom management needs above the needs of her family members” (p. 143). Schulman-Green et al. (2012) examined a similar concept of self-management as well as transitions in an ovarian cancer patient population ( $N=10$ ) and concluded that “women with ovarian cancer need clinical and social support to prioritize and manage transitions” (p. 354). This suggests that the experience of living with the diagnosis and treatment of ovarian cancer may be a form of transition that challenges an individual’s sense of self, as well as their meaning and purpose in life. That is, through the changes required to living life after the diagnosis, participants gave themselves permission to move into their authentic self. Dingley and Roux (2013), in a study testing the middle-range *Theory of Inner Strength*, reported findings that supported the concept of inner strength as a contributing factor for quality of life and self-management for women who have been diagnosed with cancer. The development of their theory included characteristics that were similar to the properties which contributed to the current study results, that is, women learning and choosing new behaviors consistent with developing or discovering an ‘authentic self’. Dingley and Roux (2013) reported that women with cancer experienced (a) anguish and searching, (b) connectedness with others, (c) engagement and self-determinism, (d) honest self-appraisal, and (e) living a new normal. Thus, the subcategory of “Now I have to take care of me” as found in the current study, was supported by findings from other research studies. That is, participants in this study reflected themes reported in the

literature, and while the small sample size does not provide direct nursing implications, nurses can provide opportunities for women to develop their self-advocacy and self-management skills.

A proposition that may be stated in relation to this subcategory includes the suggestion that women diagnosed with and treated for ovarian cancer may potentially benefit from individualized nursing interventions as they learn self-management and self-advocacy skills. Nursing research related to self-advocacy, self-management, and the transitions for women with ovarian cancer has the potential to improve quality of life. Exploring the impact of and ways to manage interpersonal dynamics may contribute to further understanding the needs of women with ovarian cancer.

### **Strengths and Limitations**

#### **Strengths.**

Strengths of the current study included the opportunity to learn about the experience of distress directly from the study participants, i.e., women diagnosed with and treated for ovarian cancer. Participants spoke candidly and, at times, paused, hesitated, and wiped away a tear, which indicated the depth of the emotional experience. Several expressed appreciation for the opportunity to share their story. Glaserian methodology (Glaser & Strauss, 1967) guided the study, meaning that the six subcategories emerged from the data and were not imposed from the investigator's preconceived ideas. Qualitative study techniques of bracketing, reflective journaling, reflexivity, maintaining a decision trail, peer review, and inclusion of a committee member with qualitative research expertise, contributed to the rigor and trustworthiness of the study. The study findings have led to the development of a theory of "existential assault" as well as a conceptual model derived from abstractions and conceptualization of content from interview

data that was collected from the full study sample ( $N=12$ ). Attrition was not a factor in this study as each participant who agreed to the interview completed the interview which provided data for analysis. Data contributed by the 12 participants provided sufficient content for constant comparative analysis with saturation noted in the theoretical coding.

### **Limitations.**

Modifications to Glaserian Grounded Theory may have contributed to study limitations. Glaserian Grounded Theory which is not modified allows the research question to be discovered as well as the “answers” to the question. That is, the research question as well as the concepts and the theories are identified in the field investigation of a social phenomenon. Unlike Glaser and Strauss’s (1967) methodology, which does not begin with any preconceived ideas nor stated research question, this study began with a specific research question. The research question, “What do women with ovarian cancer want their spouse/significant other, family, friends, and healthcare providers to know about their experience of distress during diagnosis and treatment?” was preconceived and was openly influenced by the investigator’s years of clinical experience combined with the need for scholarly inquiry.

While the six subcategories that emerged represented the experience of all 12 study participants, there were limitations to this study sample. Among the potential limitations was the broad range of ages among the study participants (ages ranged from 21 to 71). Various ages of study participants at the time of diagnosis and the age-related developmental differences may have impacted study findings. That is, developmentally, each age range has appropriate “tasks” related to successful functioning (Erikson, 1950, Erickson et al. 2013) and as such, this may have influenced study findings. For example, younger participants in the study related concerns about

reproductivity and potential long term negative health consequences while older participants focused more on tasks related to aging gracefully.

Another potential limitation was in the sampling method which involved recruitment from gynecologic oncologist offices and an e-mail list of an ovarian cancer support group. Study data may have been more “rich” had true theoretical sampling (Glaser & Strauss, 1967) been possible. For true theoretical sampling, the data collection would be guided by the findings of initial interviewer observations; therefore whatever information the investigator obtained would direct the next step in the research process. Theoretical sampling was an area of modification because data collection was limited to women diagnosed and treated for ovarian cancer, and did not include other relevant data sources such as family members, friends or healthcare providers. Therefore, study findings, while relevant to the patient population, are limited in regards to the original intent of the grounded theory method.

### **Directions for Future Research**

Grounded theory purpose according to Glaser and Strauss (1967) is to “enable prediction and explanation of behavior...to give the practitioner understanding and some control of situations...to provide a perspective on behavior...to guide and provide a style for research on particular areas of behavior” (p. 3). Findings from this study were grounded in the data and reflected the experience of the participants. This conceptual model may be useful when developed further as a theoretical framework to guide future oncology nursing research. A next step would be to determine if the findings are relevant for a wider sample of women diagnosed with and treated for ovarian cancer and verification of the emergent categories in additional qualitative and quantitative studies. This would include exploring the subcategories in terms of

renaming them into variables that could be further explored and measured. In order to test and modify the theory, surveys, with open ended questions and fixed choice answers as well as the development of new instruments, may be useful. For example, “Out of the blue like lightning” has to do with how the diagnosis was delivered to the study participants. Further inquiry about delivery of an ovarian cancer diagnosis could be generated in the form of a standardized survey sent to healthcare providers whether locally or nationally based. Taking the subcategory of “No stone left unturned” suggests the concept of being in control of one’s treatment regimen in this patient population. A survey or questionnaire to quantify treatment options and treatments received would be beneficial. The subcategory of “Knowing what I don’t want to know and not knowing what I want to know” suggests uncertainty. Uncertainty exists in many other diagnoses and it would be helpful to determine if there are specific aspects related to the uncertainty women diagnosed with and treated for ovarian cancer experience. Following up with the subcategory of “Watching you watching me- we are both afraid,” it became apparent that the needs of those intended to support women diagnosed with and treated for ovarian cancer sometimes interfered with their ability to provide support. Research studies into how to help women better negotiate relationships for support as well as exploring the support needs of the other individuals would be beneficial. In the subcategory of “Talking yet not talking, about death,” communication strategies responsive to the ability of the individual and others to talk about difficult issues would be a contribution to women diagnosed with and treated for ovarian cancer as well as a great many other patient populations. Finally, “Now I have to take care of me” relates to self-advocacy and self-management strategies and may reflect the *Theory of Inner Strength* (Dingley & Roux, 2013). The Inner Strength Questionnaire (Roux, Lewis, Younger,

and Dingley, 2004) would be an instrument for measuring a concept for this subcategory. In brief, future studies with a variety of research designs, would include exploring those measures that might capture individual concepts relevant to each subcategory and testing the propositions or the relationship between variables that build towards support of the conceptual model or theoretical framework of “Ovarian Cancer: Existential Assault.” Nurse researchers are particularly well poised to explore the impact on overall quality of life in this patient population by developing nursing interventions guided by these research opportunities

Other areas for future research would be to examine the experience for women related to their age and developmental tasks, related to the specific stages of diagnosis, and also related to the trajectory of the illness. Considering theoretical sampling, it would also be beneficial to interview others in the participant’s social network including her spouse/significant other, family, friends and healthcare providers.

### **Implications for Nursing Practice**

Generalizability and direct practice implications are not the outcome expected for grounded theory method. However, findings from this study support what other research studies have documented. On the basis of the evidence, nurses can continue to holistically (a) assess patient needs, as well as those of the spouse/significant other, family friends, and healthcare providers; (b) plan nursing interventions that take into account the psychological, psychosocial, spiritual, and physiological distress needs of women diagnosed with and treated for ovarian cancer; as well as the needs of those who provide for their support; (c) implement appropriate interventions which help the individual respond to and adjust to the new diagnosis in ways that will be beneficial and contribute to overall well-being; and (d) evaluate the effectiveness of those

interventions, altering the plan of care when new information from the patient or from research is warranted. This study has provided evidence, as related by the participants, of the needs of women diagnosed with and treated for ovarian cancer and their spouse/significant other, family friends, and healthcare providers.

## **Conclusions**

Grounded theory was used to generate a theory and a conceptual model of the experience of women diagnosed with and treated for ovarian cancer. Because it emerged from the data instead of being imposed, the resultant theory can “provide us with relevant predictions, explanations, interpretations and applications” (Glaser & Strauss, 1967, p. 1). The main points that emerged from this modified grounded theory study reflect the characterization and conceptualization of the experience as an “existential assault.” From the unexpected diagnosis, to the attempt to control the disease, and then processing the uncertainty, dealing with the emotions of others in the social network, learning how to communicate with others following the diagnosis, and finding the authentic self, participants faced experiences and decisions that were unexpected, unwelcome and perceived as potentially life threatening. The purpose of the study was to ask “What do women with ovarian cancer want others (spouse/significant other, family, friends, and healthcare providers) to know about their experience of distress during diagnosis and treatment?” While the chosen methodology focused on the emergence of a theory instead of answering the research question, the findings do help understand the experience of distress for women diagnosed with and treated for ovarian cancer. Participants also provided direct answers to the research question during the interviews (Appendix L); however, these answers contributed to the coding and the memoing but did not always reflect how the data was conceptualized.



While some research studies have examined distress in women with ovarian cancer, they have not provided clear answers about the experience due to the inconsistent definitions and measures. The current study did not contribute to the clarity of a definition or measures for distress in this population. The current study, however, provides information about the experience from the perspective of women diagnosed with and treated for ovarian cancer. Participants in this study did not define their distress in terms of the physical discomforts associated with surgery, treatment, and the progression of the disease, nor did they elaborate on spiritual distress. The physical discomforts were acknowledged, but were dismissed as being inconveniences that had resolved. For these participants, distress was experienced largely within a psychological and psychosocial context. The imposed ambiguities resulting from both the diagnosis and treatment and also from the alterations in roles and relationships created distress for these participants. At times, the participants were required to provide support for the persons that they expected to support them, which was also distressful. Study findings help us understand what contributes to the distress of women diagnosed with and treated for ovarian cancer.

The findings of this study have supported prior research including studies that emphasized the importance of helping women with self-management (Schulman-Green et al., 2012), self-advocacy (Hagan & Donovan, 2013), and the recognition of the “authentic self” (Laranjeira et al., 2013). From study findings the investigator has developed a conceptual model (Figure 1) which may contribute to further research based on the perspectives of women diagnosed with and treated for ovarian cancer. Propositions for the relationships of the subcategories have been proposed and future areas for research have been suggested. With

further research, it may be possible to intervene in ways to decrease the experience of distress for women diagnosed with and treated for ovarian cancer.

## References

## References

“Abstraction.” *Merriam-Webster.com*.2014.<http://www.merriam-webster.com/dictionary/abstraction>

Akyüz, A., Güvenc, G., Ustünsöz, A., & Kaya, T. (2008). Living with gynecologic cancer: Experiences of women and their partners. *Journal of Nursing Scholarship, 40* (3), 241-247. doi:10.1111/j.1547-5069.2008.00232.x

American Cancer Society. (2014). Ovarian cancer. Retrieved from <http://www.cancer.org/cancer/ovariancancer/index>

Andersen, B. L. (2002). Biobehavioral outcomes following psychological interventions for cancer patients. *Journal of Consulting and Clinical Psychology, 70* (3), 590-610. doi:10.1037//0022-006X.70.3.590

Andersen, B. L., & Hacker, N. F. (1983). Treatment for gynecologic cancer: A review of the effects on female sexuality. *Health Psychology, 2* (2), 203-211. doi:10.1037/02786133.2.2.203

Arden-Close, E., Gidron, Y., & Moss-Morris, R. (2008). Psychological distress and its correlates in ovarian cancer: A systematic review. *Psycho-Oncology, 17*, 1061-1072. doi:10.1002/pon.1363

“Assault.” *Merriam-Webster.com*.2014. <http://www.merriam-webster.com/dictionary/assault>

“Authentic.” *Merriam-Webster.com*.2014 <http://www.merriam-webster.com/dictionary/authentic>

Basen-Engquist, K., Bodurka-Bevers, D., Fitzgerald, K.W., Cella, D., Hu, S. & Gershenson, D. M. (2001). Reliability and validity of the functional assessment of cancer therapy-ovarian.

*Journal of Clinical Oncology*, 19 (6), 1809-1817.

Beck, A.T., Steer, R.A. & Brown, G.K. (1996) *BDI-II, Beck depression inventory manual*. San Antonio, TX: Psychological Corporation.

Bodurka-Bervers, D., Basen-Engquist, K., Carmack. C. L., Fitzgerald, M. A., Wolf, J. K., de Moor, C. & Gershenson, D. M. (2000). Depression, anxiety, and quality of life in patients with epithelial ovarian cancer. *Gynecologic Oncology*, 78, 302-308.  
doi:10.1006/gyno.2000.5908

Bowes, D. E., Tamlyn, D., & Butler, L. J. (2002). Women living with ovarian cancer: Dealing with an early death. *Health Care for Women International*, 23, 135-148.  
Doi:10.1080/073993302753429013

Bresser, P. J. C., Van Gool, A. R., Seynaeve, C. Duivenvoorden, H. J., Niermeijer, M. F., van Geel, A. N.,...Tibben, A. (2007). Who is prone to high levels of distress after prophylactic mastectomy and/or salpingo-ovariectomy? *Annals of Oncology*, 18, 1641-1645. doi:10.1093/annonc/mdm274

Burns, N. (1989). Standards for qualitative research. *Nursing Science Quarterly*, 2, 44-52.  
doi:10.1177/089431848900200112

Butow, P.N., Price, M.A., Bell, M.L., Webb, P.M., de Fazio, A., Australian Ovarian Cancer Study Group... Friedlander, M. (2014). Caring for women with ovarian cancer in the last year of life: A longitudinal study of caregiver quality of life, distress and unmet needs. *Gynecologic Oncology*. 1-8. <http://dx.doi.org/10.1016/j.jygyno.2014.002>

- Cain, E. N., Kohorn, E. I., Quinlan, D. M., Schwartz, P. E., Latimer, K., & Rogers, L. (1983). Psychosocial reactions to the diagnosis of gynecologic cancer. *Obstetrics & Gynecology*, 62 (5), 635-641.
- Canada, A. L., Parker, P., de Moor, J. S., Basen-Engquist, K., Ramondetta, L. M., & Cohen, L., (2006). Active coping mediates the association between religion/spirituality and quality of life in ovarian cancer. *Gynecologic Oncology*, 101, 102-107.  
doi:10.1016/j.ygyno.2005.09.045
- Cessario, S. K., Nelson, L. S., Broxson, A., & Cesario, A. L. (2010). Sword of Damocles cutting through the life stages of women with ovarian cancer. *Oncology Nursing Forum*, 37 (5), 609-617. doi:10.1188/10.ONF.609-617
- Cella, D., Tulskey, D.S., Gray, G., Sarafian, B., Linn, E., Bonomi, A,...Brannon, J. (1993). The functional assessment of cancer therapy scale: development and validation of the general measure. *Journal of Clinical Oncology*, 11 (3), 570-579.
- Chinn, P.L. & Kramer, M.K. (2011) *Integrated Theory and Knowledge Development in Nursing*. St. Louis, MO: Elsevier Mosby.
- Conceptualization, 2014. In *Merriam-Webster.com*.from <http://www.merriam-webster.com/dictionary/conceptualization>
- Creswell, J.W. & Miller, D.L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39 (3), 124-130.
- Dawson, T. (1993). Ovarian cancer: The experiences of women after treatment. *Journal of Cancer Care*, 2, 39-44.

- Derogatis, L.R. (1977). *SCL-90-R administration, scoring and procedures manual-1 for the revised version*. Baltimore: Johns Hopkins School of Medicine.
- Derogatis, L.R. (1986). The psychosocial adjustment to illness scale (PAIS). *Journal of Psychometric Research* 30, 1, 77-91. [http://dx.doi.org/10.1016/0022-3999\(86\)90069-3](http://dx.doi.org/10.1016/0022-3999(86)90069-3)
- Derogatis, L.R. (1993). *The brief symptom inventory (BSI) administration, scoring and procedures manual (4th ed.)*. Minneapolis, MN: National Computer systems
- Dingley, C., & Roux, G. (2013). The role of inner strength in quality of life and self-management in women survivors of cancer. *Research in Nursing & Health*, 37 (1), 32-41. doi: 10.1002/nur.21579
- Distress, 2014. In *Merriam-Webster.com*. from <http://www.merriam-webster.com/dictionary/distress>
- Elit, L., Charles, C., Gold, I., Gafni, A., Farrell, S., Tedford, S.,... Whelan, T. (2003). Women's perceptions about treatment decision making for ovarian cancer. *Gynecologic Oncology*, 88, 89-95. doi:10.1016/S0090-8258(02)00090-2
- Erickson, J.M., MacPherson, C.F., Ameringer, S., Baggott, C., Linder, L., & Stegenga, K. (2013). Symptoms and symptom clusters in adolescents receiving cancer treatment: a review of the literature. *International Journal of Nursing Studies* 50, 847-869.
- Erikson, E.H. (1950). *Childhood and Society*. New York: W.W. Norton & Company.
- Existential, 2014. In *Merriam-Webster.com*. Retrieved from <http://www.merriam-webster.com/dictionary/existential>
- Fang, C. Y., Cherry, C., Devarajan, K., Li, T., Malick, J., & Daly, M. B. (2009). A prospective study of quality of life among women undergoing risk-reducing salpingo-oophorectomy

versus gynecologic screening for ovarian cancer. *Gynecologic Oncology*, 112 (3), 594-600. doi:10.1016/j.ygyno.2008.11.039

Fawcett, J. (2005). *Contemporary Nursing Knowledge Analysis and Evaluation of Nursing Models and Theories* (2<sup>nd</sup> ed.). Philadelphia: F.A. Davis Company.

Ferrell, B., Cullinane, C. A., Ervin, K., Melancon, C., Uman, G. C., & Jaurez, G. (2005). Perspectives on the impact of ovarian cancer: Women's views of quality of life. *Oncology Nursing Forum*, 32 (6), 1143-1149. doi:10.1188/05.ONF.1143-1149

Ferrell, B.R., Dow, K.H., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of Life Research*, 4, 523-531.

Ferrell, B., Smith, S., Cullinane, C., & Melancon, C. (2003a). Symptom concerns of women with ovarian cancer. *Journal of Pain and Symptom Management*, 2 (6), 528-538. doi:10.1016/S0885-3924(03)00148-9

Ferrell, B., Smith, S. L., Cullinane, C. A., & Melancon, C. (2003b). Psychological well being and quality of life in ovarian cancer survivors. *CANCER*, 98 (5), 1061-1071. doi:10.1002/cncr.11291

Ferrell, B. R., Smith, S. L., Ervin, K. S., Itano, J., & Melancon, C. (2003). A qualitative analysis of social concerns of women with ovarian cancer. *Psycho-Oncology*, 12, 647-663. doi:10.1002/pon.681

Ferrell, B. R., Smith, S. L., Juarez, G., & Melancon, C. (2003). Meaning of illness and spirituality in ovarian cancer survivors. *Oncology Nursing Forum*, 30 (2), 249-257. doi:10.1188/03.ONF.249-257



- Fitch, M. I., Deane, K., & Howell, D. (2003). Living with ovarian cancer: Women's perspectives on treatment and treatment decision-making. *Canadian Oncology Nursing Journal*, 13 (1), 8-20.
- Fitch, M. I., Deane, K., Howell, D., & Gray, R. E. (2002). Women's experiences with ovarian cancer: Reflections on being diagnosed. *Canadian Oncology Nursing Journal*, 12 (3), 152-168.
- Fitch, M., Gray, R. E., & Franssen, E. (2000). Perspectives on living with ovarian cancer: Young women's views. *Canadian Oncology Nursing Journal*, 10 (3), 101-108.
- Frost, M.H., Johnson, M.E., Atherton, P. J., Peterson, W.O., Dose, A.M., Kasner, M.J. Burger, K.N., Sloan, J.A., & Pipe, T.B. (2012). Spiritual well-being and quality of life of women with ovarian cancer and their spouses. *Journal of Supportive Oncology*, 10, 72-80. doi: 10.1016/j.suponc.2011.09.001
- Geirdal, A. Ø., & Dahl, A. A. (2008). The relationship between psychological distress and personality in women from families with familial breast/ovarian or hereditary non-polyposis colorectal cancer in the absence of demonstrated mutations. *Journal of Genetic Counseling*, 17 (4), 384-393. doi:10.1007/s10897-008-9159-y
- Gill, P.S., & Whisnant, B. (2012). A qualitative assessment of an online support community for ovarian cancer patients. *Patient Related Outcome Measures*, 3, 51-58. doi:http://dx.doi.org/10.2147/PROM.536034
- Gioiella, M. E., Berkman, B., & Robinson, M. (1998). Spirituality and quality of life in gynecologic oncology patients. *Cancer Practice*, 6 (6), 333-338.

- Glaser, B.G. (1965). The constant comparative method of qualitative analysis. *Social Problems*, 12(4), 436-445.
- Glaser, B.G. (1978). *Advances in the methodology of grounded theory: Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B.G. (1992). *Basics of grounded theory analysis: Emerging versus forcing*. Mill Valley, CA: Sociology Press
- Glaser, B.G. (2008). *Doing quantitative grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B.G. (2012). *Stop, write: Writing grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B.G. & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Publishing Company
- Goff, B. A., Mandel, L., Muntz, H. G., & Melancon. (2000). Ovarian carcinoma diagnosis results of a national ovarian cancer survey. *Cancer*, 89(10), 2068-2075. doi:10.1002/1097-0142(20001115)89:10<2068::AID-CNCR6>3.0.CO;2-Z
- Goncalves, V., Jayson, G., & Tarrier, N. (2008). A longitudinal investigation of psychological morbidity in patients with ovarian cancer. *British Journal of Cancer*, 99, 1794-1801. doi:10.1038/sj.bjc.6604770
- Hagan, T.L., & Donovan, H.S. (2013). Ovarian cancer survivors' experiences of self-advocay: A focus group study. *Oncology Nursing Forum*, 40, 2, 140-147.
- Halstead, M. T., & Hull, M. (2001). Struggling with paradoxes: The process of spiritual development in women with cancer. *Oncology Nursing Forum*, 28 (10), 1534-1544.
- Howell, D., Fitch, M. I., & Deane, K. A. (2003a). Impact of ovarian cancer perceived by women. *Cancer Nursing*, 26 (1), 1-9.

- Howell, D., Fitch, M. I., & Deane, K. A. (2003b). Women's experiences with recurrent ovarian cancer. *Cancer Nursing*, 26 (1), 10-17.
- Howlader, N., Noone, A.M., Krapcho, M., Garshell, J., Neyman, N., Altekruse, S.F., ... Cronin, K.A. (eds). *SEER cancer statistics review, 1975-2010*. Bethesda, MD: National Cancer Institute. <http://seer.cancer.gov/statfacts/html/ovary.html> based on November 2012 SEER data submission, posted to the SEER web site, April 2013.
- Institute of Medicine (IOM). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Adler, N.E. & Page, A.E.K., eds. Washington, DC: The National Academies Press.
- Johnson, R. L., Gold, M. A., & Wyche, K. F. (2010). Distress in women with gynecologic cancer. *Psycho-Oncology*, 19, 665-668. doi:10.1002/pon.1589
- Kirkova, J., Davis, M. P., Walsh, D., Tiernan, E., O'Leary, N., LeGrand, S. B., ... Russell, K. M. (2006). Cancer symptom assessment instruments: A systematic review. *Journal of Clinical Oncology*, 24 (9), 1459-1473. doi:10.1200/JCO.2005.02.8332
- Koch, T. (2006). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 53 (1), 91-103. doi:10.1111/j.1365-2648.2006.03681.x
- Kornblith, A. B., Mirabeau-Beale, K., Lee, H., Goodman, A. K., Penson, R. T., Pereira, L., ... Matulonis, U. A. (2010). Long-term adjustment of survivors of ovarian cancer treated for advanced-stage disease. *Journal of Psychological Oncology*, 28, 451-469. doi:10.1080/07347332.2010.498458

- Laranjeira, C., Leão, P.P., & Leal, I. (2013). Meaning of life after cancer: an existential-phenomenological approach to female cancer survival. *Women Studies International Forum, 40*, 132-143.
- Levine, E. G., & Silver, B. (2007). A pilot study: Evaluation of a psychosocial program for <http://dx.doi.org/10.1016/j.wsif.2013.05.015> women with gynecological cancers. *Journal of Psychosocial Oncology, 25* (3), 75-98. doi:10.1300/J077v25n03\_05
- Liang, L. P., Dunn, S. M., Gorman, A., & Stuart-Harris, R. (1990). Identifying priorities of psychosocial need in cancer patients. *British Journal of Cancer, 62*, 1000-1003. doi:10.1038/bjc.1990.425
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- Liu, S., Ercolano, E., Seifert, M. L., & McCorkle, R. (2010). Patterns of symptoms in women after gynecologic surgery. *Oncology Nursing Forum, 37* (2), E133-E140. doi:10.1188/10.ONF.E133-E140
- Lobchuk, M. M., & Bokhari, S. A. (2008). Linkages among empathic behaviors, physical symptoms, and psychological distress in patients with ovarian cancer: A pilot study. *Oncology Nursing Forum, 35* (5), 808-814. doi:10.1188/08.ONF.808-814
- Lockwood-Rayermann, S., Donovan, H. S., Rambo, D., & Kuo, C. J. (2009). Women's awareness of ovarian cancer risks and symptoms. *American Journal of Nursing, 109* (9), 36-45. doi: 10.1097/01.NAJ.0000360309.08701.73
- Manne, S., Rini, C., Rubin, S., Rosenblum, N., Bergman, C., Edelson, M.,...Rocereto, T. (2008). Long-term trajectories of psychological adaptation among women diagnosed with

gynecological cancers. *Psychosomatic Medicine*, 70, 677-687.

doi:10.1097/PSY.0b013e31817b935d

Matulonis, U. A., Kornblith, A., Lee, H., Bryan, J., Gibson, C., Wells, C.,...Penson, R. (2008).

Long-term adjustment of early-stage ovarian cancer survivors. *International Journal of Gynecological Cancer*, 18, 1183-1193. doi:10.1111/j.1525-1438.2007.01167.x

Maughan, K., & Clarke, C. (2001). The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality. *Journal of Clinical Nursing*, 10, 221-229.

doi:10.1111/j.1365-2702.2001.00465.x

McCorkle, R., Dowd, M., Ercolano, E., Schulman-Green, D., Williams, A., Siefert, M.

L.,...Schwartz, P. (2009). Effects of a nursing intervention on quality of life outcome in post-surgical women with gynecological cancers. *Psycho-Oncology*, 18, 62-70.

doi:10.1002/pon.1365

McCorkle, R., Pasacreta, J., & Tang, S. T. (2003). The silent killer: Psychological issues in ovarian cancer. *Holistic Nursing Practice*, 17, 300-308.

McNair, D.M., Lorr, M., & Droppleman, L.F. (1971). *Profile of mood states*. San Diego: Educational and Industrial Testing Service.

Morris, M. E., Grant, M., & Lynch, J.C. (2007). Patient-reported family distress among long-term cancer survivors. *Cancer Nursing*, 30 (1), 1-8.

National Comprehensive Cancer Network. (2014). *NCCN Clinical Practice Guidelines in Oncology Ovarian Cancer version 1.2014*. Retrieved from National Comprehensive Cancer Network: [www.nccn.org](http://www.nccn.org)

National Comprehensive Cancer Network. (2013). *NCCN Distress Management Guidelines version 2.2013*. Retrieved from National Comprehensive Cancer Network:  
[www.nccn.org](http://www.nccn.org)

Norton, T. R., Manne, S. L., Rubin, S., Carlson, J., Hernandez, E., Edelson, M. I.,...Bergman, C. (2004). Prevalence and predictors of psychological distress among women with ovarian cancer. *Journal of Clinical Oncology*, 22 (5), 919-926. doi:10.1200/JCO.2004.07.028

Norton, T. R., Manne, S. L., Rubin, S., Hernandez, E., Carlson, J., Bergman, C., & Rosenblum, N. (2005). Ovarian cancer patients' psychological distress: The role of physical impairment, perceived unsupportive family and friend behaviors, perceived control, and self-esteem. *Health Psychology*, 24 (2), 143-152. doi:10.1037/0278-6133.24.2.143

Oncology Nursing Society. (2014, June). *Implementing Screening for Distress: The Joint Position Statement From the American Psychosocial Oncology Society, Association of Oncology Social Work, and Oncology Nursing Society*. Retrieved from  
<https://www.ons.org/about-ons/ons-position-statements/nursing-practice/implementing-screening-distress-joint-position>

O'Sullivan, C. K., Bowles, K. H., Jeon, S., Ercolano, E., & McCorkle, R. (2011). Psychological distress during ovarian cancer treatment: Improving quality by examining patient problems and advanced practice nursing interventions. *Nursing Research and Practice*. Article ID 351642, 14 pages. doi:10.1155/2011/351642

Paloutzian, R.F., & Ellison, C.W. (1982). Loneliness, spiritual well-being and the quality of life. In. Peplau, L.A., Perlman, D., (Eds). *Loneliness: A Sourcebook of Current Theory, Research, and Therapy*. New York: John Wiley & Sons.

“Phenomena.” *Merriam-Webster.com*.2014 <http://www.merriam-webster.com/dictionary/phenomena>

“Physiological.” *Merriam-Webster.com*.2014 <http://www.merriam-webster.com/dictionary/physiological>

“Psychological.” *Merriam-Webster.com*.2014 <http://www.merriam-webster.com/dictionary/psychological>

“Psychosocial.” In *Merriam-Webster.com*.2014 <http://www.merriam-webster.com/dictionary/psychosocial>

Ponto, J. A., Ellington, L., Mellon, S., & Beck, S. L. (2010). Predictors of adjustment and growth in women with recurrent ovarian cancer. *Oncology Nursing Forum*, 37 (3), 357-364.  
doi:10.1188/10.ONF.357-364

Portenoy, R. K., Kornblith, A. B., Wong, G., Vlamis, V., Lepore, J. M., Loseth, D. B.,...Hoskins, W. J. (1994a). Pain in ovarian cancer patients. *Cancer*, 74 (3), 907-915.  
doi:10.1002/1097-0142(19940801)74:3<907::AID-CNCR2820740318>3.0.CO;2-#

Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Kiyasu, E. ...Norton, L. (1994b). The memorial symptom assessment scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer*, 30A, 9, 1326-36.

Power, J., Brown, L., & Ritvo, P. (2008). A qualitative study examining psychosocial distress, coping, and social support across the stages and phases of epithelial ovarian cancer. *Health Care for Women International*, 29, 366-383. doi:10.1080/07399330701876521

- Powers, B.A. & Knapp, T.R. (2011). *Dictionary of Nursing Theory and Research* (fourth ed.). New York: Springer Publishing Company.
- Prat, J. [for the FIGO Committee on Gynecologic Oncology]. (2014). Staging classification for cancer of the ovary, fallopian tube, and peritoneum. *International Journal of Gynecology and Obstetrics*, 24, 1-5. doi:<http://dx.doi.org/10.1016/j.ijgo.2013.10.001>
- Price, M. A., Butow, P. N., Costa, D. S. J., King, M. T., Aldridge, L. J., Fardell, J. E.,... Webb, P. M. (2010). Prevalence and predictors of anxiety and depression in women with invasive ovarian cancer and their caregivers. *The Medical Journal of Australia*, 193 (5), S52-S57.
- Radloff, L.S. (1977). The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.  
doi: 10.1177/014662167700100306
- Reb, A. M. (2007). Transforming the death sentence: Elements of hope in women with ovarian cancer. *Oncology Nursing Forum*, 34 (6), E70-E81. doi:10.1188/07.ONF.E70-E81
- Rose, S.L., Spencer, R. J., & Rausch, M.M. (2013). The use of humor in patients with recurrent ovarian cancer. *International Journal of Gynecological Cancer*, 12, 4, p. 775-779. doi: 10.1097/IGC.0b013e31828addd5
- Rossing, M. A., Wicklund, K. G., Cushing-Haugen, K. L., & Weiss, N. S. (2010). Predictive value of symptoms for early detection of ovarian cancer. *Journal of National Cancer Institute*, 102 (4), 222-229. doi:10.1093/jnci/djp500
- Roux, G., Lewis, K., Younger, J. & Dingley, C. (2006). Development and testing of the inner strength questionnaire. *Journal of Cultural Diversity*, 10, 4-5.



- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8 (3), 27-37.
- Schipper, H., Clinch, J., McMurray, A., & Levitt, M. (1984). Measuring the quality of life of cancer patients: the functional living index: cancer: development and validation. *Journal of Clinical Oncology*, 2 (5), 472-483.
- Schmidt, N.A., & Brown, J.M. (Eds.) (2012). *Evidence-Based Practice for Nurses: Appraisal and Application of Research*. Sudbury, Massachusetts: Jones and Bartlett Publishers.
- Schulman-Green, D., Bradley, E.H., Nicholson, N.R., George, E., Indeck, A., & McCorkle, R. (2012). One step at a time: Self-management and transitions among women with ovarian cancer. *Oncology Nursing Forum* 39, 4, 354-360. doi: 10.1188/12.ONF.354-360
- Starr, S. S. (2008). Authenticity: A concept analysis. *Nursing Forum*. Volume 43, 2. 55-62.
- Spielberger, C.D., Gorsuch, R.L., Lushene, R., Vagg, P.R., & Jacobs, G.A. (1983). *Manual for the state-trait anxiety inventory*. Palo Alto, CA: Consulting Psychologists Press.
- Stead, M. L., Fallowfield, L., Selby, P., & Brown, J. M. (2007). Psychosexual function and impact of gynaecological cancer. *Best Practice & Research. Clinical Obstetrics and Gynaecology*, 21(2), 309-320. Doi:10.1016/j.bpobgyn.2006.11.008
- Strauss, A.L. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications, Inc.
- “Substantive.” *Merriam-Webster.com*.2014 <http://www.merriam-webster.com/dictionary/substantive>
- Sukegawa, A., Miyagi, E., Asai-Sato, M., Saji, H., Sugiura, K., Matsumura, T.,...Hirahara, F. (2008). Anxiety and prevalence of psychiatric disorders among patients awaiting surgery

- for suspected ovarian cancer. *Journal of Obstetrics and Gynecology Research*, 32 (3), 349-353. doi:10.1111/j.1447-0756.2008.00738.x
- Sukegawa, A., Miyagi, E., Suzuki, R., Ogasawara, T., Asai-Sato, M., Yoshida, H.,...Hirahara, F. (2006). Post-traumatic stress disorder in patients with gynecologic cancers. *Journal of Obstetrics and Gynaecological Research*, 32 (3), 349-353. doi:10.1111/j.1447-0756.2006.00409.x
- Suzuki, N., Ninomiya, M., Maruta, S., Honsonuma, S., Nishigaya, Y., Kobayashi, Y.,...Ishizuka, B. (2011). Psychological characteristics of Japanese gynecologic cancer patients after learning the diagnosis according to the hospital anxiety and depression scale. *The Journal of Obstetrics and Gynaecology Research*, 37 (7), 800-808. doi:10.1111/j.1447-0756.2010.01437.x
- Swenson, M. M., MacLeod, J. S., Williams, S. D., Miller, A. M., & Champion, V. L. (2003). Quality of living among ovarian germ cell cancer survivors: A narrative analysis. *Oncology Nursing Forum*, 30 (3), E56-E62. doi:10.1188/03.ONF.E56-E62
- Villagomez, L. R. (2005). Spiritual distress in adult cancer patients. *Holistic Nursing Practice*, 19 (6), 285-294.
- Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. *Journal of the National Cancer Institute*, 102 (21), 1464-1488. doi:10.1093/jnci/djp336
- Von Gruenigen, V. E., Frasure, H. E., Jenison, E. L., Hopkins, M. P., & Gil, K. M. (2006). Longitudinal assessment of quality of life and lifestyle in newly diagnosed ovarian cancer

- patients: The roles of surgery and chemotherapy. *Gynecologic Oncology*, 103, 12-126.  
doi:10.1016/j.ygyno.2006.01.059
- Walker, L. & Myrick, F. (2006). Grounded theory: an exploration of process and procedure. *Qualitative Health Research*, 16 (4), 547-559. doi: 10.1177/1049732305285972
- Weisman, A.D. & Worden, J.W. (1976). The existential plight in cancer: significance of the first 100 days. *The International Journal of Psychiatry in Medicine*, 7, 1, 1-15.
- Wilmoth, M. C., Hatmaker-Flanigan, E., LoLoggia, V., & Nixon, T. (2011). Ovarian cancer survivors: Qualitative analysis of the symptom of sexuality. *Oncology Nursing Forum*, 38 (6), 699-707. doi:10.1188/11.ONF.699-708
- Zabora, J., Brintzenhofesoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10, 19-28.
- Ziebland, S., Evans, J., & McPherson, A. (2006). The choice is yours? How women with ovarian cancer make sense of treatment choices. *Patient Education and Counseling*, 62, 361-367.  
doi:10.1016/j.pec.2006.06.014
- Zigmond, A.S., & Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

## Appendices

## Appendix A

Virginia Commonwealth University IRB original approval 01-03-2013



Office of Research Subjects Protection  
 BioTechnology Research Park  
 BioTech One, 800 E. Leigh Street, Suite 3000  
 P.O. Box 980568  
 Richmond, Virginia 23298-0568  
 (804) 828-0868  
 (804) 827-1448 (fax)

DATE: January 3, 2013

TO: Debra E. Lyon, PhD, RN, FNP-BC, FNAP, FAAN  
 School of Nursing  
 Box 980567

FROM: Lise M. Abrams, PhD  
 Chairperson, VCU IRB Panel B  
 Box 980568

RE: VCU IRB #: HM14824  
 Title: Distress in Women with Ovarian Cancer

On January 2, 2013, the following research study was approved by expedited review according to 45 CFR 46.110 Categories 6 and 7. The approval reflects the revisions received in the Office of Research Subjects Protection on December 20, 2012. This approval includes the following items reviewed by this Panel:

**RESEARCH APPLICATION/PROPOSAL:** None

**PROTOCOL (Research Plan):** Distress in Women with Ovarian Cancer, received 12/20/12, version date 12/20/12

- VCU IRB Study Personnel Roster, received 11/2/12, version 2, dated 8/10/12
- Demographic Questions (Appendix E), received 12/20/12, version date 12/20/12
- Interview Guide (Appendix F), received 12/20/12, version date 12/20/12
- References (Appendix G), received 12/20/12, version date 12/20/12

**CONSENT/ASSENT (attached):**

- Research Subject Information and Consent Form, received 12/20/12, version date 12/20/12, 3 pages

**ADDITIONAL DOCUMENTS (attached):**

- Distress Letter (Appendix A), received 12/20/12, version date 12/20/12
- Brochure (Appendix B), received 12/20/12, version date 12/20/12
- Print Invitation (Appendix C), received 12/20/12, version date 12/20/12

**This approval expires on December 31, 2013.** Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at [lusry@mcvh-vcu.edu](mailto:lusry@mcvh-vcu.edu) and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at [irbpanelb@vcu.edu](mailto:irbpanelb@vcu.edu) and 828-3992.

*[Attachment – Conditions of Approval]*

**Conditions of Approval:**

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must (as applicable):

1. Conduct the research as described in and required by the Protocol.
2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).
3. Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent is specifically approved).
4. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translated version.
5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants (e.g., permanent/temporary change of PI, addition of performance/collaborative sites, request to include newly incarcerated participants or participants that are wards of the state, addition/deletion of participant groups, etc.). Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).
6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.
7. Report Unanticipated Problems (UPs), including protocol deviations, following the VCU IRB requirements and timelines detailed in VCU IRB WPP VIII-7:
8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of research participants.
9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.
10. All protocols that administer acute medical treatment to human research participants must have an emergency preparedness plan. Please refer to VCU guidance on <http://www.research.vcu.edu/irb/guidance.htm>.
11. The VCU IRBs operate under the regulatory authorities as described within:
  - a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
  - b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
  - c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

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### RESEARCH SUBJECT INFORMATION AND CONSENT FORM

**TITLE: Distress in Women with Ovarian Cancer**

**VCU IRB NO.: HM14824**

This consent form may contain words that you do not understand. Please ask about any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

#### PURPOSE OF THE STUDY

The purpose of this research study is to find out about the experience of distress, if any, for women with ovarian cancer and what they would like for others (spouse/significant other, family, friends, and healthcare providers) to know about their distress experience. We would like to better understand how women would like to be supported, especially when they experience distress. You are being asked to participate in this study because you are a woman who has been diagnosed with ovarian cancer.

#### DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen with the study.

This study will explore your experience with distress, if any, and what you would like others to know. Your participation in this study will include one audiotaped interview which is expected to take between one to two hours. You are free to stop the interview at any time. Approximately 20 women will participate in this study. The interview will be audiotaped to be sure that we include all your ideas, but your name will not be used. If identifying information is accidentally recorded, it will be removed when the interview is transcribed to a printed document.

You may contact the interviewer if you have additional thoughts or questions. If you would like to know the results of the completed research, you will need to let the interviewer know and provide contact information.

If we learn new information during the course of the research that may affect your willingness to continue participating in the study, we will provide it to you and you may withdraw.

If you choose to participate in this study, you will be asked to do the following:

- Sign this consent form
- Provide demographic information for the purpose of describing the study results. Examples of demographic information include age and education. You may refuse to answer any of the demographic questions.
- Participate in a 1-2 hour audio-taped interview to discuss your experience with distress, if any, and what you would like others to know about that experience.

#### RISKS AND DISCOMFORTS

We don't expect anyone to be harmed any more than in daily life. At the same time, sometimes talking about these subjects causes people to become upset. You do not have to talk about any subjects you do not want to talk about, and you may leave at any time. If you become upset, you are advised to contact your healthcare provider or spiritual advisor so you can get help in dealing with these issues.

#### BENEFITS TO YOU AND OTHERS

This is not a treatment study and you may not get any direct benefit from your participation in this study. The information we learn from women in this study may benefit other patients in the future.

#### COSTS

**APPROVED**

1-2-13 / L... / SR



There are no costs for participating in this study other than the time you will spend in the interview. You will receive a \$25.00 gift certificate at the completion of the interview.

#### ALTERNATIVES

The Alternative to participating in this study is to not participate in this study.

#### CONFIDENTIALITY

Potentially identifiable information about you will consist of demographic information and is being collected for research purposes only with access limited to study personnel. This information, along with the audio tapes will be stored in a locked research area and destroyed after the completion of the study. Interview transcripts with fictional names will be kept indefinitely in a password protected computer file. What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

Information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by the sponsor of the research, or by Virginia Commonwealth University. In the event that you disclose information that you may cause injury to yourself or others, I am required by law to report that information to the appropriate authorities.

Virginia Commonwealth University and Virginia Commonwealth University Health Systems, also known as Medical College of Virginia Hospital do not have a plan to give long term care or money if you are injured because you are in the study. If you are injured because of being in this study, report it right away to the interviewer or to the principal investigator listed on the consent form. We will arrange for short term emergency care or referral if it is needed. Bills for treatment may be sent to you or your insurance company. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

#### VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. If you choose to withdraw from this study there will be no penalty or loss of care, service or benefit from Virginia Commonwealth University or the Health System. Your participation in this study may be stopped at any time by the principal investigator. The reasons might include:

- it is necessary for your health, well-being, or safety
- you have not followed study instructions
- administrative reasons require your withdrawal

If you leave the study voluntarily, you may be asked by the principal investigator why you decided to leave. You do not have to respond if you do not wish.

#### QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Judith DellaRipa, MS, RN, FNP-BC Virginia Commonwealth University School of Nursing 1100 E. Leigh Street P.O. Box 980567	Debra Lyon, PhD, RN, FNP-BC, FNAP, FAAN Virginia Commonwealth University School of Nursing 1100 E. Leigh Street P.O. 980567
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APPROVED

1-2-12/lu/jr

Richmond, VA 23298 804-683-2895 <a href="mailto:dellaripaja@vcu.edu">dellaripaja@vcu.edu</a> Student investigator	Richmond, VA 23298 804-828-5635 <a href="mailto:delyou@vcu.edu">delyou@vcu.edu</a> Primary Investigator
--	--

If you have any questions about your rights as a participant in this study, you may contact

**Office for Research**  
Virginia Commonwealth University  
800 East Leigh Street, Suite 113  
P.O. Box 980568  
Richmond, VA 23298  
Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

#### CONSENT

*I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.*

Participant name printed	Participant signature	Date
<hr/>		
Name of Person Conducting Informed Consent Discussion / Witness (Printed)		Date
<hr/>		
Signature of Person Conducting Informed Consent Discussion / Witness		Date
<hr/>		
Principal Investigator Signature (if different from above)		Date
<hr/>		

APPROVED

12-23/2012 / JRC



Virginia Commonwealth University School of Nursing  
Judith Dellaripa MS, RN, FNP-BC  
DEBRA E. LYNN, PhD, RN, FNP-BC, PHAP, FAAN

# RESEARCH STUDY FOR WOMEN WITH OVARIAN CANCER

*What would you like others to know about  
your experience of distress?*



**YOU MAY BE ELIGIBLE FOR THIS STUDY IF YOU  
HAVE BEEN DIAGNOSED WITH OVARIAN  
CANCER, ARE BETWEEN THE AGES OF 18-60,  
AND ARE WILLING TO PARTICIPATE IN AN IN-  
DEPTH INTERVIEW. PARTICIPANTS WILL  
RECEIVE A \$25.00 GIFT CARD.**

**FOR MORE INFORMATION CONTACT JUDITH  
DELLARIPA : 804-683-2895 OR E-MAIL:  
DELLARIPAJA@VCU.EDU**

**APPROVED**

1-2-13 / 24 / JJC

Judith Dellaripa  
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804-683-2895

Judith Dellaripa  
804-683-2895

Judith Dellaripa  
804-683-2895

Judith Dellaripa  
804-683-2895

DISTRESS IN WOMEN  
WITH OVARIAN CANCER

This is a study through  
Virginia Commonwealth University  
School of Nursing

1100 East Leigh Street  
Richmond, VA 23298-0567

Contact information:

Judith DellaRipa MS, RN, FNP-BC

dellaripaja@vcu.edu

804-683-2895

Principle Investigator

Debra E. Lyon, PhD, RN,

FNP-BC, FNAP, FAAN

delyon@vcu.edu

Appendix B Brochure  
12-20-2012



APPROVED

1-2-13 / LU / JR

January 2013

Judith DellaRipa

Research Study for Women with  
Ovarian Cancer

WHAT WOULD  
YOU LIKE  
OTHERS TO  
KNOW ABOUT  
YOUR  
EXPERIENCE OF  
DISTRESS?



## DISTRESS



What would women with ovarian cancer like for their spouse/ significant other, family, friends and healthcare providers to know about their experience of distress during diagnosis and treatment?

Have you experienced distress? Researchers have looked at distress in women with ovarian cancer and clinicians are interested in helping to decrease the experience of distress.

***BUT WHAT DO WOMEN  
SAY ABOUT THEIR  
EXPERIENCE?***

Interviews will be conducted by an experienced nurse in a private location such as an office within the school of nursing or a public place of your choosing.

You may be eligible to participate if you:

- ◆ Have been diagnosed with ovarian cancer, stage I, II, III, IV, or recurrence
- ◆ Are between the ages of 18-60
- ◆ Speak English
- ◆ Are not pregnant
- ◆ Are willing to participate in an a 1-2 hour interview
- ◆ Sign a consent form

Your privacy will be maintained and you will receive a \$25.00 gift card for participating. For accuracy, the interviews will be audiotaped and transcribed. Your participation is voluntary and the interview may be stopped at any time, or you may refuse to answer any of the questions. The information we learn from women in this study may benefit others in the future.



**APPROVED**

1-2-13 / Lw / DR



Print version for handing to potential participants or to send electronically.

An Opportunity to Participate in Individual Interviews Asking What Women with Ovarian Cancer would Like Others to Know about Their Experience of Distress

Dear Potential Participant,

If you have been diagnosed and treated for ovarian cancer, I would like to talk with you. Was distress a part of your experience? Researchers and clinicians believe that women with ovarian cancer experience distress. I would like to invite you to participate in a study exploring what women would like for their spouse/significant other, family, friends, and health care providers to know about their experience of distress.

This voluntary research study is being conducted in the Richmond, Virginia area through Virginia Commonwealth University School of Nursing and Massey Cancer Center. Women between the ages of 18-60, who are willing to participate in an audio taped interview, are eligible. If you decide not to participate, your decision will have no consequences or affect the health care you receive.

If you would like to discuss your unique experiences, please contact the student investigator at dellaripaja@vcu.edu or call 804-683-2895 for more information and to arrange an interview time and location that is convenient for you.

Thank you for reading this letter.

Kind regards,

Judith DellaRipa MS, RN, FNP-BC

APPROVED

1-2-13 / LK / JDR

## Appendix B

Letter of recruitment support from referring physician 05-20-2013



May 20, 2013

Debra E. Lyon, PhD, RN, FNP-BC, FNAP, FAAN  
C/o Judith DellaRipa MS, RN, FNP-BC  
6451 Lakeway Drive  
Mechanicsville, Virginia 23111  
[dellaripaja@vcu.edu](mailto:dellaripaja@vcu.edu)  
Phone #804-683-2895

Re: Letter of Permission for research activity: "*Distress in Women with Ovarian Cancer*"  
Principal Investigator: Debra Lyon PhD  
IRB of record: Virginia Commonwealth University IRB

Dear Dr. Lyon,

Thank you for requesting this letter of permission for the above noted nursing research project. Virginia Gynecologic Oncology grants permission for the sub-investigator and PhD candidate, Judith DellaRipa, to place recruitment materials for this research in the office of Virginia Gynecologic Oncology located at 7603 Forest Avenue Suite 207, Richmond, VA 23229.

Sincerely,  


Cecelia Boardman, MD  
Virginia Gynecologic Oncology  
(804) 200-7062

Cc: Debra E. Lyon, PhD, Judith DellaRipa FNP, Cecelia Boardman MD

7603 Forest Avenue, Suite 207, Richmond, VA 23229  
Phone 804-200-7062 Fax 804-200-7003



## Appendix C

Virginia Commonwealth University IRB approval for age revision 03-18-2013



Office of Research Subjects Protection  
BioTechnology Research Park  
BioTech One, 800 E. Leigh Street, Suite 3000  
P.O. Box 980568  
Richmond, Virginia 23298-0568  
(804) 828-0868  
(804) 827-1448 (fax)

DATE: March 21, 2013

TO: Debra E. Lyon, PhD, RN, FNP-BC, FNAP, FAAN  
School of Nursing  
Box 980567

FROM: Lisa M. Abrams, PhD  
Chairperson, VCU IRB Panel B  
Box 980568

RE: **VCU IRB #: HM14824**  
**Title: Distress in Women with Ovarian Cancer**

On March 18, 2013, the changes to your research study were **approved** in accordance with 110 (b) (2). This approval includes the following items reviewed by this Panel:

**PROTOCOL (Research Plan):** Distress in Woman with Ovarian Cancer, received 3/8/13, version date 3/4/13

**ADDITIONAL DOCUMENTS (attached):**

- Tear-Off Flyer: Research Study for Women with Ovarian Cancer, received 3/8/13, version date 3/4/13
- Brochure (Appendix B), received 3/8/13, version date 3/4/13
- Print Invitation (Appendix C), received 3/8/13, version date 3/4/13

**As a reminder, the approval for this study expires on December 31, 2013.** Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at [lusry@mcvh-vcu.edu](mailto:lusry@mcvh-vcu.edu) and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at [irbpanelb@vcu.edu](mailto:irbpanelb@vcu.edu) and 828-3992.

Lyon/DellaRipa Research plan 03-04-2013

Virginia Commonwealth University School of Nursing  
Judith DellaRipa MS, RN, FNP-BC  
Debra E. Lyon, PhD, RN, FNP-BC, TNAAP, FAAN



# RESEARCH STUDY FOR WOMEN WITH OVARIAN CANCER

*What would you like others to know about  
your experience of distress?*



**YOU MAY BE ELIGIBLE FOR THIS STUDY IF YOU  
HAVE BEEN DIAGNOSED WITH OVARIAN  
CANCER, ARE OVER THE AGE OF 18, AND ARE  
WILLING TO PARTICIPATE IN AN IN-DEPTH  
INTERVIEW. PARTICIPANTS WILL RECEIVE A  
\$25.00 GIFT CARD.**

**FOR MORE INFORMATION CONTACT JUDITH  
DELLARIPA : 804-683-2895 OR E-MAIL:  
DELLARIPAJA@VCU.EDU**

**APPROVED**

3-18-13 / LV / JJJ

Judith DellaRipa  
804-683-2895

Judith DellaRipa  
804-683-2895

Judith DellaRipa  
804-683-2895

Judith DellaRipa  
804-683-2895

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Judith DellaRipa  
804-683-2895

DISTRESS IN WOMEN  
WITH OVARIAN CANCER

This is a study through  
Virginia Commonwealth University  
School of Nursing

1100 East Leigh Street  
Richmond, VA 23298-0567

Contact information:

Judith DellaRipa MS, RN, FNP-BC

dellaripaja@vcu.edu

804-683-2895

Principle Investigator

Debra E. Lyon, PhD, RN,

FNP-BC, FNAP, FAAN

delyon@vcu.edu

Appendix B Brochure

03-04-2013



Research Study for Women with  
Ovarian Cancer

WHAT WOULD  
YOU LIKE  
OTHERS TO  
KNOW ABOUT  
YOUR  
EXPERIENCE OF  
DISTRESS?



APPROVED

3-78-13 / LLD / JDR

January 2013

Judith DellaRipa

## DISTRESS



What would women with ovarian cancer like for their spouse/ significant other, family, friends and healthcare providers to know about their experience of distress during diagnosis and treatment?

Have you experienced distress? Researchers have looked at distress in women with ovarian cancer and clinicians are interested in helping to decrease the experience of distress.

***BUT WHAT DO WOMEN  
SAY ABOUT THEIR  
EXPERIENCE?***

Interviews will be conducted by an experienced nurse in a private location such as an office within the school of nursing or a public place of your choosing.

You may be eligible to participate if you:

- ◆ Have been diagnosed with ovarian cancer, stage I, II, III, IV, or recurrence
- ◆ Are age 18 or older
- ◆ Speak English
- ◆ Are not pregnant
- ◆ Are willing to participate in an a 1-2 hour interview
- ◆ Sign a consent form

Your privacy will be maintained and you will receive a \$25.00 gift card for participating. For accuracy, the interviews will be audiotaped and transcribed. Your participation is voluntary and the interview may be stopped at any time, or you may refuse to answer any of the questions. The information we learn from women in this study may benefit others in the future.



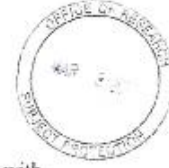
APPROVED

3-18-13 / LC / DC

Appendix C print invitation

03-04-2013

Print version for handing to potential participants or to send electronically



An Opportunity to Participate in Individual Interviews Asking What Women with Ovarian Cancer would Like Others to Know about Their Experience of Distress

Dear Potential Participant,

If you have been diagnosed and treated for ovarian cancer, I would like to talk with you. Was distress a part of your experience? Researchers and clinicians believe that women with ovarian cancer experience distress. I would like to invite you to participate in a study exploring what women would like for their spouse/significant other, family, friends, and health care providers to know about their experience of distress.

This voluntary research study is being conducted in the Richmond, Virginia area through Virginia Commonwealth University School of Nursing and Massey Cancer Center. Women over the age of 18, who are willing to participate in an audio taped interview, are eligible. If you decide not to participate, your decision will have no consequences or affect the health care you receive.

If you would like to discuss your unique experiences, please contact the student investigator at dellaripaja@vcu.edu or call 804-683-2895 for more information and to arrange an interview time and location that is convenient for you.

Thank you for reading this letter.

Kind regards,

Judith DellaRipa MS, RN, FNP-BC

APPROVED

3-18-13 / LV / JN2

## Appendix D

Virginia Commonwealth University IRB change in Primary Investigator (PI)

revision 12-19-2013



Office of Research Subjects Protection  
 BioTechnology Research Park  
 BioTech One, 800 E. Leigh Street, Suite 3000  
 P.O. Box 980568  
 Richmond, Virginia 23298-0568  
 (804) 828-0868  
 (804) 827-1448 (fax)

DATE: December 19, 2013

TO: Victoria S. Menzies, PhD, Ed.M., MSN, BA  
 School of Nursing  
 Box 980567

FROM: Lisa M. Abrams, PhD  
 Chairperson, VCU IRB Panel B  
 Box 980568

RE: VCU IRB #: HM14824  
 Title: Distress in Women with Ovarian Cancer

On December 19, 2013, this research study was approved for continuation by expedited review according to 45 CFR 46.108(b) and 45 CFR 46.109(e) and 45 CFR 46.110 Categories 6 and 7. This determination reflects the revisions received in the Office of Research Subjects Protection on December 13, 2013.

**VCU IRB APPROVED CONSENT/ASSENT FORM:** None (Enrollment Complete)

In addition, changes to your research study were approved in accordance with 110 (b) (2). This approval includes the following items reviewed by this Panel:

**PROTOCOL (Research Plan):** Distress in Women with Ovarian Cancer, received 12/13/13, version date 12/13/13

- VCU IRB Study Personnel Roster, received 12/13/13, version date 12/13/13

**Please Note:** The VCU IRB acknowledges the change in Principal Investigator from Debra Lyon, PhD, to Victoria Menzies, PhD.

**This approval expires on November 30, 2014.** Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at [lusry@mcvh-vcu.edu](mailto:lusry@mcvh-vcu.edu) and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at [irbpanelb@vcu.edu](mailto:irbpanelb@vcu.edu) and 828-3992.

[Attachment – Conditions of Approval]



**Conditions of Approval:**

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must (as applicable):

1. Conduct the research as described in and required by the Protocol.
2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).
3. Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent is specifically approved).
4. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translated version.
5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants (e.g., permanent/temporary change of PI, addition of performance/collaborative sites, request to include newly incarcerated participants or participants that are wards of the state, addition/deletion of participant groups, etc.). Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).
6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.
7. Report Unanticipated Problems (UPs), including protocol deviations, following the VCU IRB requirements and timelines detailed in VCU IRB WPP VIII-7:
8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of research participants.
9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.
10. All protocols that administer acute medical treatment to human research participants must have an emergency preparedness plan. Please refer to VCU guidance on <http://www.research.vcu.edu/irb/guidance.htm>.
11. The VCU IRBs operate under the regulatory authorities as described within:
  - a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
  - b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
  - c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

[010507]

## Appendix E

Virginia Commonwealth University IRB recruitment site revision 05-21-2013

and 07-19-2013



Office of Research Subjects Protection  
BioTechnology Research Park  
BioTech One, 800 E. Leigh Street, Suite 3000  
P.O. Box 980568  
Richmond, Virginia 23298-0568  
(804) 828-0868  
(804) 827-1448 (fax)

DATE: May 21, 2013

TO: Debra E. Lyon, PhD, RN, FNP-BC, FNAP, FAAN  
School of Nursing  
Box 980567

FROM: Lisa M. Abrams, PhD  
Chairperson, VCU IRB Panel B  
Box 980568

RE: VCU IRB #: HM14824  
Title: Distress in Women with Ovarian Cancer

*J. K. Rice  
for L. Abrams*

On May 21, 2013, the changes to your research study were approved in accordance with 110 (b) (2). This approval includes the following items reviewed by this Panel:

**PROTOCOL (Research Plan):** Distress in Women with Ovarian Cancer, received 5/9/13, version date 5/6/13

**ADDITIONAL DOCUMENTS (attached):**

- Print Invitation (Appendix C), received 5/9/13, version date 5/6/13

**As a reminder, the approval for this study expires on December 31, 2013.** Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at [lusry@mcvh-vcu.edu](mailto:lusry@mcvh-vcu.edu) and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at [irbpanelb@vcu.edu](mailto:irbpanelb@vcu.edu) and 828-3992.

Appendix C print invitation 05-06-2013  
Print version for handing to potential participants or to send electronically



An Opportunity to Participate in Individual Interviews Asking What Women with  
Ovarian Cancer would Like Others to Know about Their Experience of Distress

Dear Potential Participant,

If you have been diagnosed and treated for ovarian cancer, I would like to talk with you. Was distress a part of your experience? Researchers and clinicians believe that women with ovarian cancer experience distress. I would like to invite you to participate in a study exploring what women would like for their spouse/significant other, family, friends, and health care providers to know about their experience of distress.

This voluntary research study is being conducted in the Richmond, Virginia area through Virginia Commonwealth University School of Nursing. Women over the age of 18, who are willing to participate in an audio taped interview, are eligible. If you decide not to participate, your decision will have no consequences or affect the health care you receive.

If you would like to discuss your unique experiences, please contact the student investigator at dellaripaja@vcu.edu or call 804-683-2895 for more information and to arrange an interview time and location that is convenient for you.

Thank you for reading this letter.

Kind regards,

Judith DellaRipa MS, RN, FNP-BC

APPROVED

5-21-13 / LU / OVR



Office of Research Subjects Protection  
 BioTechnology Research Park  
 BioTech One, 800 E. Leigh Street, Suite 3000  
 P.O. Box 980568  
 Richmond, Virginia 23298-0568  
 (804) 828-0868  
 (804) 827-1448 (fax)

DATE: July 19, 2013

TO: Debra E. Lyon, PhD, RN, FNP-BC, FNAP, FAAN  
 School of Nursing  
 Box 980567

FROM: Lisa M. Abrams, PhD  
 Chairperson, VCU IRB Panel B  
 Box 980568

RE: VCU IRB #: HM14824  
 TITLE: Distress in Women with Ovarian Cancer

The VCU IRB acknowledges receipt of the following document for the above referenced study on July 1, 2013:

- Research Subject Information and Consent Form for Bon Secours participants (approved by the Bon Secours IRB on June 25, 2013).
- Bon Secours IRB Approval Letter (dated June 25, 2013).

**As a reminder, the approval for this study expires on December 31, 2013.** Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

If you have any questions, please contact Dr. Lisa Abrams, Chairperson, VCU IRB Panel B, at [lmabrams@vcu.edu](mailto:lmabrams@vcu.edu) and 827-2627; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at [irbpanelb@vcu.edu](mailto:irbpanelb@vcu.edu) and 828-3992.

**Judith Dellaripa**

---

**From:** jlrice@vcu.edu on behalf of VCU IRBPANELB <irbpanelb@vcu.edu>  
**Sent:** Monday, July 22, 2013 4:52 PM  
**To:** Debra E Lyon  
**Cc:** Judith A DellaRipa  
**Subject:** IRB Letter of Acknowledgement for Expedited Study #HM14824  
**Attachments:** B-HM14824-07-19-2013.pdf

Dr. Lyon,

The IRB letter of acknowledgement for the review of materials from the Bon Secours Health System in relation to your expedited study #HM14824 is attached. Since Bon Secours has a separate IRB review in place for this study and specific materials to be used for their participants, there is no need for VCU to conduct an additional approval on their behalf. The materials reviewed will be kept in the VCU IRB record for reference.

Jennifer L. Rice, BS, CIP  
IRB Panel B Administrator  
Office of Research Subjects Protection - MCV Campus  
800 E. Leigh Street, Suite 3000  
P.O. Box 980568  
Richmond, VA 23298-0568  
(804) 828-3992 (804) 827-1448 fax  
[jlrice@vcu.edu](mailto:jlrice@vcu.edu)

**Judith Dellaripa**

---

**From:** jlrice@vcu.edu on behalf of VCU IRBPANELB <irbpanelb@vcu.edu>  
**Sent:** Wednesday, July 24, 2013 11:57 AM  
**To:** Judith Dellaripa  
**Subject:** Re: IRB Letter of Acknowledgement for Expedited Study #HM14824

Hi Judy,

Since Bon Secours has approved their own consent form for use with their participants and we are not their IRB of record, we are not approving their consent rather just acknowledging that we received and reviewed it. The Bon Secours consent should be used for those participants, and the VCU approved consent used for others. Please let me know if you have any other questions. Thanks, Jenny

On Tue, Jul 23, 2013 at 9:37 AM, Judith Dellaripa <dellaripaja@vcu.edu> wrote:

Jennifer,

My question is in regards to the consent form. I understood that I need to use the one that is approved by VCU on January 3. So now I have one that has been approved by the Bon Secours IRB, but it does not have the VCU approval on it. Will this be a problem? Thank you for your help in this process!

Judith DellaRipa

**From:** jlrice@vcu.edu [mailto:jlrice@vcu.edu] **On Behalf Of** VCU IRBPANELB  
**Sent:** Monday, July 22, 2013 4:52 PM  
**To:** Debra E Lyon  
**Cc:** Judith A DellaRipa  
**Subject:** IRB Letter of Acknowledgement for Expedited Study #HM14824

Dr. Lyon,

The IRB letter of acknowledgement for the review of materials from the Bon Secours Health System in relation to your expedited study #HM14824 is attached. Since Bon Secours has a separate IRB review in place for this study and specific materials to be used for their participants, there is no need for VCU to conduct an additional approval on their behalf. The materials reviewed will be kept in the VCU IRB record for reference.

Jennifer L. Rice, BS, CIP  
IRB Panel B Administrator  
Office of Research Subjects Protection - MCV Campus  
800 E. Leigh Street, Suite 3000

1

## Appendix F

Bon Secours Richmond Healthsystem IRB Approval 06-25-2013





June 25, 2013

Debra Lyon, PhD, RN, FNP-BC, FNAP, FAAN  
Virginia Commonwealth University  
PO Box 980567  
Richmond, VA 23298  
ATTN: Judith DellaRipa

VCU DellaRipa: Distress in Women with Ovarian Cancer

Dear Dr. Lyon,

This study with accompanying application materials submitted to the Bon Secours Richmond Health System IRB on June 5, 2013, was **approved** on June 25, 2013, by expedited review according to 45 CFR 46.110 Categories 6 and 7, and the attached Conditions of Approval. Only the attached **Bon Secours Richmond Health System IRB APPROVED and STAMPED CONSENT FORM** may be used to enroll subjects in your study.

This approval expires on **June 24, 2014**. Federal Regulations and Bon Secours Richmond Health System IRB require continuing review prior to continuation past that date. Continuing review notification will be sent to you prior to the next scheduled review.

Please direct any questions to Mark Leep at [mark\\_leep@bshsi.org](mailto:mark_leep@bshsi.org) or (804) 627-5157.

Sincerely,

A handwritten signature in black ink, appearing to read "Gerald Keightley, III".

Dr. Gerald Keightley, III  
Chair, Institutional Review Board

Attachments: Conditions of Approval; Research Subject Information and Consent Form (BSR IRB approval date of June 25, 2013)

RESEARCH SUBJECT INFORMATION AND CONSENT FORM  
Virginia Commonwealth University and Bon Secours Richmond Health System



**TITLE:** Distress in Women with Ovarian Cancer  
**Investigator:** Judith DellaRipa MS, RN, FNP-BC

**VCU IRB NO.:** 14824  
**Bon Secours IRB No.:**

This consent form may contain words that you do not understand. Please ask about any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

**PURPOSE OF THE STUDY**

The purpose of this research study is to find out about the experience of distress, if any, for women with ovarian cancer and what they would like for others (spouse/significant other, family, friends, and healthcare providers) to know about their distress experience. We would like to better understand how women would like to be supported, especially when they experience distress. You are being asked to participate in this study because you are a woman who has been diagnosed with ovarian cancer.

**DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT**

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen with the study.

This study will explore your experience with distress, if any, and what you would like others to know. Your participation in this study will include one audiotaped interview which is expected to take between one to two hours. You are free to stop the interview at any time. Approximately 20 women will participate in this study. The interview will be audiotaped to be sure that we include all your ideas, but your name will not be used. If identifying information is accidentally recorded, it will be removed when the interview is transcribed to a printed document.

You may contact the interviewer if you have additional thoughts or questions. If you would like to know the results of the completed research, you will need to let the interviewer know and provide contact information.

If we learn new information during the course of the research that may affect your willingness to continue participating in the study, we will provide it to you and you may withdraw.

If you choose to participate in this study, you will be asked to do the following:

- Sign this consent form
- Provide demographic information for the purpose of describing the study results. Examples of demographic information include age and education. You may refuse to answer any of the demographic questions.
- Participate in a 1-2 hour audio-taped interview to discuss your experience with distress, if any, and what you would like others to know about that experience.

**RISKS AND DISCOMFORTS**

We don't expect anyone to be harmed any more than in daily life. At the same time, sometimes talking about these subjects causes people to become upset. You do not have to talk about any subjects you do not want to talk about, and you may leave at any time. If you become upset, you are advised to contact your healthcare provider or spiritual advisor so you can get help in dealing with these issues.

**BENEFITS TO YOU AND OTHERS**

1 of 3

This is not a treatment study and you may not get any direct benefit from your participation in this study. The information we learn from women in this study may benefit other patients in the future.

#### **COSTS**

There are no costs for participating in this study other than the time you will spend in the interview. You will receive a \$25.00 gift certificate at the completion of the interview.

#### **ALTERNATIVES**

The Alternative to participating in this study is to not participate in this study.

#### **CONFIDENTIALITY**

Potentially identifiable information about you will consist of demographic information and is being collected for research purposes only with access limited to study personnel. This information, along with the audio tapes will be stored in a locked research area and destroyed after the completion of the study. Interview transcripts with fictional names will be kept indefinitely in a password protected computer file. What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

Information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by the sponsor of the research, or by Virginia Commonwealth University and Bon Secours Richmond Health System. In the event that you disclose information that you may cause injury to yourself or others, I am required by law to report that information to the appropriate authorities.

Virginia Commonwealth University, Virginia Commonwealth University Health Systems, also known as Medical College of Virginia Hospital and Bon Secours Richmond Health System do not have a plan to give long term care or money if you are injured because you are in the study. If you are injured because of being in this study, report it right away to the interviewer or to the principal investigator listed on the consent form. We will arrange for short term emergency care or referral if it is needed. Bills for treatment may be sent to you or your insurance company. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

#### **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. If you choose to withdraw from this study there will be no penalty or loss of care, service or benefit from Virginia Commonwealth University Health Systems or the Bon Secours Richmond Health System. Your participation in this study may be stopped at any time by the principal investigator. The reasons might include:

- it is necessary for your health, well being, or safety
- you have not followed study instructions
- administrative reasons require your withdrawal

If you leave the study voluntarily, you may be asked by the principal investigator why you decided to leave. You do not have to respond if you do not wish.



2 of 3

### QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Judith DellaRipa, MS, RN, FNP-BC Virginia Commonwealth University School of Nursing 1100 E. Leigh Street P.O. Box 980567 Richmond, VA 23298 804-683-2895 <a href="mailto:jdellaripaja@vcu.edu">jdellaripaja@vcu.edu</a> Student investigator	Debra Lyon, PhD, RN, FNP-BC, FNAP, FAAN Virginia Commonwealth University School of Nursing 1100 E. Leigh Street P.O. 980567 Richmond, VA 23298 804-828-5635 <a href="mailto:delyon@vcu.edu">delyon@vcu.edu</a> Primary Investigator
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If you have any questions about your rights as a participant in this study, you may contact

Office for Research Virginia Commonwealth University 800 East Leigh Street, Suite 113 P.O. Box 980568 Richmond, VA 23298 Telephone: 804-827-2157	Bon Secours Richmond Health System Institutional Review Board 8580 Magellan Parkway Richmond, Virginia 23227 804-627-5157
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You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

### CONSENT

*I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.*

Participant name printed	Participant signature	Date
_____ Name of Person Conducting Informed Consent Discussion / Witness (Printed)	_____	_____
_____	_____	_____
Signature of Person Conducting Informed Consent Discussion / Witness	_____	_____
_____	_____	_____
Principal Investigator Signature (if different from above)	_____	_____



3 of 3

## Appendix G

### Recruitment materials

## Informational Brochure outerfold

### DISTRESS IN WOMEN WITH OVARIAN CANCER

This is a study through  
Virginia Commonwealth University  
School of Nursing

1100 East Leigh Street  
Richmond, VA 23298-0567

Contact information:

Judith DellaRipa MS, RN, FNP-BC

dellaripaja@vcu.edu

804-683-2895

Principle Investigator

Debra E. Lyon, PhD, RN,

FNP-BC, FNAP, FAAN

delyon@vcu.edu



January 2013  
Judith DellaRipa

Research Study for Women with  
Ovarian Cancer

WHAT WOULD  
YOU LIKE  
OTHERS TO  
KNOW ABOUT  
YOUR  
EXPERIENCE OF  
DISTRESS?



## Informational Brochure innerfold



### Distress



What would women with ovarian cancer like for their spouse/ significant other, family, friends and healthcare providers to know about their experience of distress during diagnosis and treatment?

Have you experienced distress? Researchers have looked at distress in women with ovarian cancer and clinicians are interested in helping to decrease the experience of distress.

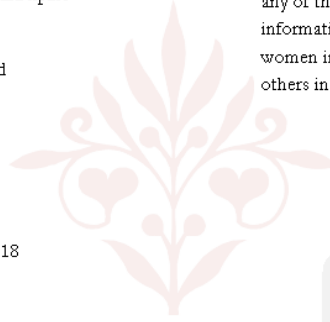
***BUT WHAT DO WOMEN SAY  
ABOUT THEIR  
EXPERIENCE?***

Interviews will be conducted by an experienced nurse in a private location such as an office within the school of nursing or a public place of your choosing.

You may be eligible to participate if you:

- ◆ Have been diagnosed with ovarian cancer, stage I, II, III, IV, or recurrence
- ◆ Are over the age of 18
- ◆ Speak English
- ◆ Are not pregnant
- ◆ Are willing to participate in an a 1-2 hour interview
- ◆ Sign a consent form

Your privacy will be maintained and you will receive a \$25.00 gift card for participating. For accuracy, the interviews will be audiotaped and transcribed. Your participation is voluntary and the interview may be stopped at any time, or you may refuse to answer any of the questions. The information we learn from women in this study may benefit others in the future.



## Print/e-mail invitation

### An Opportunity to Participate in Individual Interviews Asking What Women with Ovarian Cancer would Like Others to Know about Their Experience of Distress

Dear Potential Participant,

If you have been diagnosed and treated for ovarian cancer, I would like to talk with you. Was distress a part of your experience? Researchers and clinicians believe that women with ovarian cancer experience distress. I would like to invite you to participate in a study exploring what women would like for their spouse/significant other, family, friends, and health care providers to know about their experience of distress.

This voluntary research study is being conducted in the Richmond, Virginia area through Virginia Commonwealth University School of Nursing and Massey Cancer Center. Women over the age of 18, who are willing to participate in an audio taped interview, are eligible. If you decide not to participate, your decision will have no consequences or affect the health care you receive.

If you would like to discuss your unique experiences, please contact the student investigator at dellaripaja@vcu.edu or call 804-683-2895 for more information and to arrange an interview time and location that is convenient for you.

Thank you for reading this letter.

Kind regards,

Judith DellaRipa MS, RN, FNP-BC



## Appendix H

### Glossary of Terms

## Appendix H Glossary of terms

### **Abstraction**

Abstraction means “a general idea or quality rather than an actual person, object, or event”

(<http://www.merriam-webster.com/dictionary/abstraction>).

In grounded theory, abstraction is taking the substantive data and coding it or categorizing it according to theoretical properties as an inductive method.

### **Assault**

Assault means “a threat or attempt to inflict offensive physical contact or bodily harm on a person... that puts the person in immediate danger of or in apprehension of such harm or contact”

(<http://www.merriamwebster.com/dictionary/assault>).

For the findings of this study, participants experienced more than an existential crisis when given the diagnosis of ovarian cancer which has poor statistical prognosis. They were aware that even with treatment, long term survivors of ovarian cancer are rare.

### **Authentic**

Authentic means “real or genuine... true and accurate” (<http://www.merriam-webster.com/dictionary/authentic>).

The *authentic self* emerged over time as the participants learned how to cope with the new reality of being diagnosed with and treated for ovarian cancer, but was not a static process and was not completed for the participants of this study.

### **Conceptual model/Conceptual framework**

A conceptual model is “a set of interrelated concepts that symbolically represent and conveys a mental image of a phenomenon” and the terms conceptual model and conceptual framework may be used interchangeably. (Powers & Knapp, 2011, p. 26).

### **Credibility**

“*Credibility* (paralleling internal validity) is demonstrated by accuracy and validity of findings that are assured through documentation of researcher actions, opinions, and biases;...appropriateness of data (e.g. purposeful sampling, intensive engagement with and observation of the phenomenon); adequacy of the database (e.g. saturation); verification/corroboratorion by use of multiple data sources (e.g. triangulation); validation of data by informants (e.g. member checks); and consultation with colleagues (e.g. peer debriefing)” (Powers & Knapp, 2011, p. 192).

### **Coding**

“Coding need consist only of noting categories on margins but it can be done more elaborately (e.g., on cards)” (Glaser & Strauss, 1967, p. 106) as well as a “unit of analysis” (Glaser & Strauss, 1967, p. 25).

#### **Axial coding.**

Axial coding is “A set of procedures whereby data are put back together in new ways after open coding, by making connections between categories” (Strauss & Corbin, 1990, p. 96).

#### **Line by line coding.**

Line by line coding means that the researcher works to “...*analyze the data line by line*, constantly coding each sentence” (Glaser, 1978, p. 57).

#### **Open coding or substantive coding.**

Open coding means that there is “...coding the data in everyway [sic] possible... or ‘running the data open’. .... diametrically contrasted with a preconceived code” (Glaser, 1978, p. 56).

#### **Selective coding.**

For selective coding, "...the analyst delimits his coding to only those variables that relate to the core variable in sufficiently significant ways..." (Glaser, 1978, p. 61).

### **Theoretical coding.**

"Theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into the theory. They, like substantive codes, are emergent. They weave the fractured story back together again" (Glaser, 2005, p. 2).

### **Conceptualization**

Conceptualization means "to form a concept of... especially to interpret conceptually" and is used in the grounded theory method (<http://www.merriam-webster.com/dictionary/conceptualization>).

### **Confirmability**

"Confirmability (paralleling objectivity) is demonstrated by providing substantiation that findings and interpretations are grounded in the data (i.e. links between researcher assertions and the data are clear and credible) and that the audit trail is complete, comprehensible, useful, and linked to the methodological approach that was used (i.e., confirmation of auditability.)" (Powers & Knapp, 2011, p. 192).

### **Constant Comparative Method**

"Methods of constant comparison refer to constant data monitoring that involves (a) comparing collected data with incoming data being coded into categories to elucidate the properties of categories; (b) integrating categories and their properties to identify patterns; and in GTM [Grounded Theory Method], (c) delimiting the theory to clarify the logic, facilitate theoretical saturation of categories, and ensure parsimony" (Powers & Knapp, 2011, p. 28).

### **Dependability**

“*Dependability* (paralleling reliability) is demonstrated by a research process that is carefully documented to provide evidence of how conclusions were reached and whether, under similar circumstances, another researcher might expect to obtain similar findings (i.e., the concept of the audit trail)” (Powers & Knapp, 2011, p. 192).

### **Distress**

Distress means “unhappiness or pain; suffering that affects the mind or body”.

(<http://www.merriam-webster.com/dictionary/distress>)

From the NCCN 2013 Distress Management Guidelines

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment.

Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (p. Dis-2)

### **Ethnography**

“As a process it involves an attitude inclined toward learning from rather than studying persons in order to understand their lifeways[sic] and worldviews in cultural context” (Powers & Knapp, 2011, p. 54).

### **Emergence**

“From the very moment a research project is begun, a grounded theory is systematically and inductively arrived at through covariant ongoing collection and analysis of data. It has a fresh start, open to the emergent. One does not begin with preconceived ideas or extant theory

and force them on data for the purpose of verifying them or rearranging them into a corrected grounded theory. Grounded theory is done without this burden and excess baggage.” Glaser, 1992, p. 15).

The investigator discovered that emergence was not predictable, but did happen reliably after spending time with the data and thinking about the meanings and relationships. Comparing the data within, between, and among the interviews created the opportunity to see hidden patterns as well as similarities and differences.

### **Existential**

Existential means “of, relating to, or affirming existence” (<http://www.merriam-webster.com/dictionary/existential>)

Participants in the study were aware that being given the diagnosis of ovarian cancer was related to their personal mortality, thus impacting their future days and quality of life.

### **Hand sorting**

“Sorting needs to be done manually on a large table that will accommodate the piles and piles of memos. And the researcher should be able to leave the piles in tact [sic] anytime, for his respites, thinking and other facets of his/her life and then return to pick up exactly where left off, on the next pile to sort. ... And, briefly, sorting cannot be accomplished by a computer program...Its integration is too varied, complex and flexible as it emerges for a computer to track. Hiring someone to sort will also not work. Really, only the original researcher knows enough of all the conceptual meanings, to properly sort memos” (Glaser, 2012, p47-48).

### **Memos/Memoing**

“In qualitative research, analytic note writing (referred to as *memos/memoing* in grounded theory) is an expected aspect of the research process. It occurs across the life of the research and is a record of the ideas that the researcher has about the nature of the data and how different concepts may be linked to one another” (Powers & Knapp, 2011, p. 106).

### **Phenomena (singular) /phenomenon (plural)**

Phenomena (singular) or phenomenon (plural) is “an observable fact or event: an object or aspect known through the senses rather than by thought or intuition” (<http://www.merriam-webster.com/dictionary/phenomenon>).

### **Physiological**

Physiological means a “characteristic of or appropriate to an organism’s healthy or normal functioning” (<http://www.merriam-webster.com/dictionary/physiological>)

### **Proposition**

Proposition is defined as a “...statement of the relation between two or more concepts” by Fawcett (2005, p. 4). Powers & Knapp (2011) indicate that a proposition is “a statement about the relationships between concepts in a theory” (p. 144).

### **Psychological**

Psychological means “of or relating to the mind” (<http://www.merriam-webster.com/dictionary/psychological>).

### **Psychosocial**

Psychosocial is understood as “involving both psychological and social aspects” (<http://www.merriam-webster.com/dictionary/psychosocial>).

### **Reflexivity**

“In qualitative research, the term reflexivity refers to a continuous process of critical self-reflection on one’s personal biases, preconceived notions, assumption, theoretical predispositions, and ideological commitments” (Powers & Knapp, 2011, p. 155).

### **Rigor**

Schmidt and Brown (2012) refer to rigor as the trustworthiness criteria of credibility, transferability, dependability, and confirmability. They define trustworthiness as the “quality, the authenticity, and the truthfulness of findings” (p. 354).

### **Social network**

For this study, the participant’s social network included her spouse/significant other, family, friends, and healthcare providers.

### **Substantive**

Substantive means “important, real, or meaningful: supported by facts or logic” (<http://www.merriam-webster.com/dictionary/substantive>).

### **Theory**

#### **Grounded theory.**

“The grounded theory approach is a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area” (Glaser, 1992, p. 16).

#### **Glaserian grounded theory.**

“Grounded theory allows the relevant social organization and socialpsychological [sic] organization of the people studied to be discovered, to emerge-- in their perspective! Grounded theory does justice to the data” (Glaser, 1992, p. 5)



### **Formal theory.**

Formal theory is “developed for a formal, or conceptual, area of sociological inquiry, such as stigma, deviant behavior, formal organization, socialization, status congruency, authority and power, reward systems, or social mobility” (Glaser & Strauss, 1967, p. 32).

### **Substantive theory.**

Substantive theory is “developed for a substantive, or empirical, area of sociological inquiry, such as patient care, race relations, professional education, delinquency, or research organizations” (Glaser & Strauss, 1967, p. 32). Substantive theory is also defined as “... at a level that is close to a specific problem and/or population” (Powers & Knapp, 2011, p. 177). Glaser (2012) relates that it “... occurs within the boundaries of a set of data” (p. 10).

### **Theoretical framework**

Chinn and Kramer (2011) define theoretic or conceptual model as a “logical grouping of related concepts or theories that usually is created to draw together several different aspects that are relevant to a complex situation, such as a practice setting or an educational program” (p.157).

### **Theoretical sampling**

“Theoretical sampling is a type of purposeful sampling that is used in grounded theory research. As data are concurrently collected and analyzed, the researcher decides what further information is needed to develop the emerging theory” (Powers & Knapp, 2011, p. 184). “[T]he process of data collections for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (Glaser, 1992, p. 101).

### **Theoretical saturation**

“*Saturation* means that no additional data are being found whereby the sociologist can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated” (Glaser & Strauss, 1967, p. 61).

### **Transferability**

“*Transferability* (paralleling external validity) is demonstrated by a report that contains sufficient information for readers to determine whether findings are meaningful to other persons in similar situations (analytic or theoretical, vs. statistical generalizability)” (Powers & Knapp, 2011, p. 192).

### **Validity**

“Qualitative researchers may use other terms such as truth value, credibility, trustworthiness, and accuracy to describe their concerns about the soundness of their data” (Powers & Knapp, 2011, p. 198).

Appendix I

Decision trail

### *Decision Trail*

Date	Study events
01-03-2013	VCU IRB approval
01-23-2013	Recruitment presentation to VCU GYN tumor board and gynecologic oncology nurse practitioner
02-08-2013	First interview- transcribed by researcher and verified by peer reviewer. Beginning of constant comparative analysis process with coding and memoing
02-15-2013	Second interview- Professionally transcribed (and all subsequent interviews)
02-27-2013	Third interview
03-21-2013	VCU IRB approval of change in age from 18-60 to over age 18
04-01-2013	meeting with new committee member to review methodology (experienced with Glaserian grounded theory)
05-04-2013	Recruitment-Northern Virginia Ovarian Cancer Coalition (NOCC) sent out e-mail invitation
05-09-2013	Fourth interview
05-21-2013	Recruitment from referring physician's new location
06-03-2013	Recruitment - <i>Run Like a Girl Marathon</i> fundraising event
06-06-2013	Fifth interview
06-14-2013	Sixth interview
06-17-2013	Seventh interview
06-19-2013	Eighth interview
06-29-2013	Bon Secours IRB approval

07-05-2013	Fifth interview reviewed by peer reviewer
07-10-2013	Ninth interview
07-19-2013	Tenth interview- theoretical saturation
07-29-2013	Recruitment- Bon Secours Outpatient Infusion Center
08-26-2013	Eleventh interview
08-30-2013	Twelfth interview
10-22-2103	Hand sorting of data. Constant comparative analysis has been ongoing since the first interview.
10-31-2013	Saturation confirmed with 12 interviews. No longer recruiting.
11-04-2013	Meeting with committee member to review method
11-15-2013	Meeting with peer reviewer to refine sub categories
12-19-2013	VCU IRB approval for Continuing Review and change of PI
12-31-2013	Informal review of subcategories by colleagues from women's surgical oncology unit
05-13-2104	VCU and Bon Secours study closed

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## Appendix J

### Interview guide

**Title: Distress in Women with Ovarian Cancer**

*The participant will be informed about the purpose of the interview and the topics to be covered and will be assured regarding the confidentiality of all information.*

**A. Introduction**

Thank you for agreeing to meet with me. Research indicates that some women with ovarian cancer experience distress. When women talk about their experience, they use different words and phrases, many of which are interpreted as indicating distress. Some of the terms, such as anxiety and depression have medical meaning as well as common meanings. Additionally, women express concern about their spouse/significant other, family, and friends during the course of the disease. Some express frustration when their communication, especially to healthcare providers does not contribute to the plan of care while others do not consider their emotional experience as part of the medical picture.

This research study would like to find out what women would like others to know about their experience, if any, of distress. Each individual interview will be examined for the significant concepts and then compared with other interviews for common themes. The results of the study will contribute a better understanding of women's experience.

Obviously this subject matter is very personal in nature. I want to let you know how privileged I feel that you are willing to share this information with me. If our conversation becomes too upsetting, for you at any time- do not hesitate to stop me. You may refuse to answer any questions. You have the right to stop and/or withdraw from the study at any point. I will be taping our interview so that I can create a transcribed print document to help me with the analysis. I may be making notes to help me remember important information. You may review my notes at any time during the interview.

**B. Demographic information**

I would like to begin with some general information. You do not have to answer any questions you do not want to. If you have questions about the items, please let me know. I will be recording your answers and making clarifying notes on a form which you may review and alter at any time during the course of the interview.

*A. The interview will then proceed guided by Glaser's Grounded Theory Methodology. The emphasis is on learning what is important for the participants to share, with themes emerging from the data. Therefore, open ended questions and free flowing conversation will be the main content of the interview. The following bullet points will be used as needed to clarify content:*

- What is the most important thing you would like for me, your spouse/significant other, family, friends, and healthcare providers to know about your experience as a woman with ovarian cancer?
- People often assume that women with ovarian cancer experience distress. Has that been true for you?
- What words do you use to talk about your distressful experiences?
- Is distress related to physical or psychosocial symptoms or to spiritual concern or does it affect your quality of life?
- Can you give an example of a time when you experienced distress?
- What would you like others to know about your experience of distress?

**D. Closure:**

I don't have any more questions for you today. Is there something that I didn't ask that you would like to add because you feel that it is important for me to know?

Thank you for sharing your thoughts and feelings with me today. As I mentioned at the beginning of the interview, you will not be identified in any way with the information you have given me. It is possible that later on I will need to contact you again to clarify your comments or to follow up on a new topic related to the experience of distress in ovarian cancer. If this is okay with you, may I get your phone number and/or mailing address to contact you? If you need to contact me or the principal investigator, please use the contact information on the consent form.

## Appendix K

Demographic form



#### Demographic Information Questions

The following questions will be asked during the interview. Specific identifying information will not be included. Pseudonyms or generic phrases will be substituted for identifying information during transcription.

Today's date	Answers	Clarifying information
<b>Age today:</b> 18-29 30-39 40-49 50-60		
<b>Marital status:</b> Single Married Divorced/separated Partnered or in a significant relationship widowed		
<b>Children:</b> Ages Living at home?		
<b>Family or friend support:</b> Local Long distance		
<b>Race/ethnicity:</b> Caucasian African American Asian Other		
<b>Education completed:</b> 8 <sup>th</sup> grade or less High School College Graduate School Trade or Technical School Other		
<b>Occupation:</b>		
<b>Employment status:</b> Full time Part time Retired Work from home Actively working Disabled		
<b>Household income:</b> \$50,00 or below Between \$50,00 and \$100,00 Over \$100,000 Health insurance		

<b>Religion/spirituality:</b> Prayer Meditation Church attendance Other?		
<b>Age and stage (I,II, III, or IV) at diagnosis:</b> 18-29 30-39 40-49 50-60		
<b>Current disease stage:</b> I II III IV Remission Recurrence		
<b>Treatments:</b> Surgery Chemotherapy Radiation Complementary or Holistic		
<b>Other major medical conditions</b>		
<b>Are you a caregiver for anyone</b>		
<b>Additional information that you think is important</b>		

## Appendix L

Direct responses to the research question

## Direct Responses to the Research Question

Participants did offer answers to the research question. These answers were included in the coding and hand sorting processes of the grounded theory method. Some of the direct answers to the research question contributed to the development of the final subcategories. Because Glaserian grounded theory does not focus on full conceptual description, many of the poignant comments were not included in the theory write up. For example, some comments were personal and contributed to the development of a subcategory, but did not capture the essence of the group expression. The following comment, from an older participant contributed to the development of the subcategory of “Now I have to take care of me,” but was not highlighted because no other interview or memo content supported it as a separate section.

At 71, the issue of not being able to have more children has not been an issue. But, with the hair loss, and bloated tummy, chronic fatigue, and spending a LOT of time at various medical appointments, I do feel less feminine and desirable, and that bothers me. So whatever anyone can do to remind me that “I’m still me” helps.

General comments included “I’d like to...I want to think of something besides cancer every day.” And one participant observed that she was “given a second chance at life, [and] I gained the opportunity to fight for others. It also made me mature quicker, but in addition challenged everything that I once believed in and made me reconsider those beliefs.” And yet another participant was able to articulate that she wants a doctor who listens to her and treats her

like a person instead of a doctor who treats the cancer. Several participants addressed comments to healthcare providers.

Give patients hope or something to believe in. I noticed personally once I allowed doubts to fill my mind, negativity followed. My treatment schedule got extremely repetitive and it was easy to get into low spirits. I found myself questioning whether or not I was mentally strong enough to overcome my circumstances.

I give them specific advice about not delivering terrible news to people when they're by themselves. Which means encourage all patients to always bring someone with...to the office with them...and if a person can't or doesn't, if you've got to deliver bad news you make sure you have a nurse or somebody else on your staff that's in the room, and that that person is an empathetic kind of a person.

Participants also addressed their family and friends. One was able to articulate the difference between overreaction and under reaction and expressed discomfort when someone responded with an over protective attitude. She knew her experience was upsetting for those around her, but she didn't want every sneeze to be suspect and she wanted to be able to enjoy normal moments. A simple interaction with her two year old nephew affirmed her as a person and helped her move forward as a survivor. Another participant found the following words for her family.

So I guess if I could say to people, to my family... (pause) I don't want to burden you with what I'm being burdened with. I'd like you to understand, but I don't want you to go...I don't want you to suffer the way I'm suffering. Um, I'd like you to be supportive

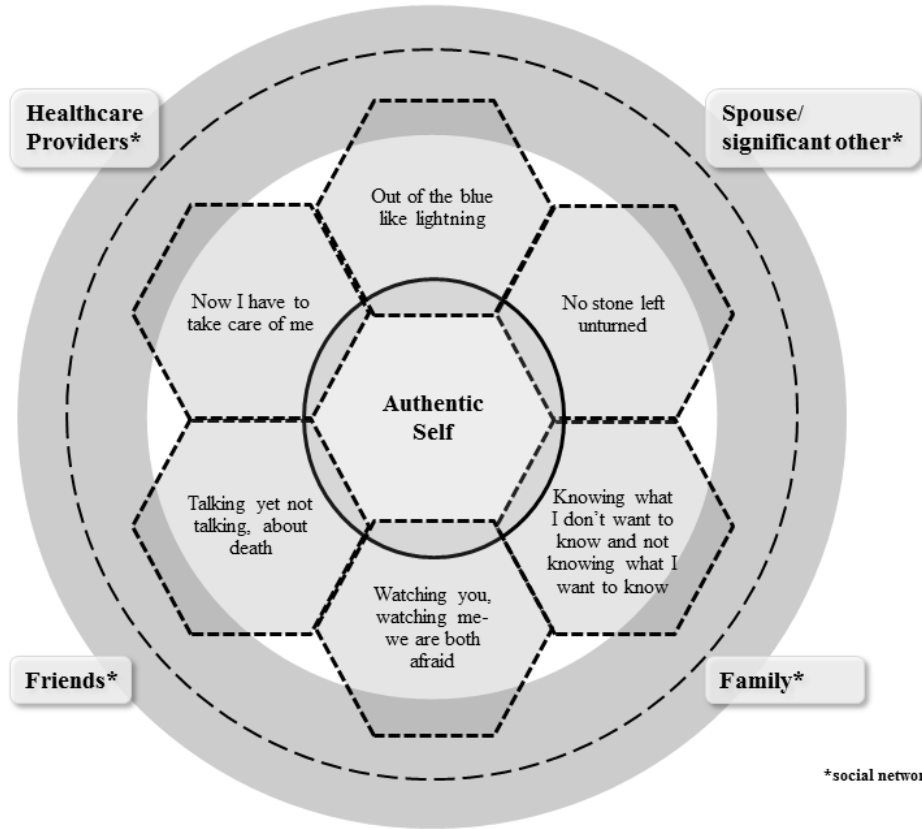
and understand when I say sometimes I don't feel well or I just can't do it today. Say, 'Okay, I understand.'... [its] not helpful for you to say, um, 'Oh, you're just being lazy,' or, 'You're just giving up,' or, um, ...just say, 'Okay, well, we'll do it today,' or, 'We could do it next time,' or, 'What can I do to help today?' 'What can I do to make you feel better?' or...or, 'It's going to be'... Even if you just say, 'It's going to be okay,' just tell me it's going to be okay. Maybe it isn't going to be okay, but I need to hear it's going to be okay, you know? Um, and and...I...maybe I don't tell you everything that's happening, but...because I don't want you to be mentally burdened the way I'm mentally burdened. Um, I'd like your support, but I don't want you to be scared the way I'm scared, even though I try not to be scared. I guess that's what I would tell them is I'm very...I'm scared, but I'm trying not to be. ...I'm not always strong, but I'm trying to be strong.

Direct answers to the research question were not always captured in the coding, abstraction, and conceptualization which were required for grounded theory. Therefore, the direct answers that participants provided were not always reflected in the theory that emerged. However, the interview content provided rich data which contributes to understanding what women would like others to know about their experience of distress.

Figure 1

Conceptual Model of “Ovarian Cancer: Existential Assault”

# Ovarian Cancer: Existential Assault





## Vita

Judith Ann DellaRipa was born November 10, 1954 in South Bend, Indiana and is an American citizen. She graduated with a Bachelor of Science from the College of Nursing at the University of Tennessee Health Science Center in Memphis in 1978. She worked as a staff nurse from 1988-2006 at Bon Secours St.Mary's Hospital on the Women's Medical Surgical and Women's Surgical Oncology unit. She received her Masters of Science in 2007 from Virginia Commonwealth University School of Nursing. She has worked as an Advanced Practice Nurse at Bon Secours St. Mary's Hospital for the Medical Surgical Division since 2010.