

**INVESTIGATION OF THE LINKAGE BETWEEN EMPATHIC INFORMAL  
CAREGIVER BEHAVIORS, PHYSICAL SYMPTOM EXPERIENCES, AND  
PSYCHOLOGICAL DISTRESS EXPERIENCED BY OVARIAN CANCER  
PATIENTS**

BY

SONIA ANWER BOKHARI

A Thesis Submitted to the  
Faculty of Graduate Studies  
In Partial Fulfillment of the Requirements for the Degree of

**MASTER OF NURSING**

Faculty of Nursing  
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## ABSTRACT

Ovarian cancer remains a leading cause of mortality for women. It generally has a poor prognosis due to its non-specific initial presentation and resultant advanced stage disease (Yawn, Barrette, & Wollan, 2004). Consequently, a diagnosis of ovarian cancer is often particularly distressing. Although a relationship between psychological distress and physical symptom experience has been previously established (Norton et al., 2005), there remains great variability between levels of psychological distress amongst patients. This suggests that the relationship between psychological distress and symptom experience is influenced by other factors, such as social support from family and friends.

Overall this study was guided by the *Stress, Appraisal, and Coping Theory* developed by Lazarus and Folkman (1984) that was adapted to conceptualize the influence of perceived social support, or empathic behaviors of “informal caregivers” on psychological distress and physical symptoms experienced by ovarian cancer patients. Using a descriptive correlational design, a convenience sample of ovarian cancer patients completed a demographic questionnaire, The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), The Empathic Responding Scale (O’Brien & Delongis, 1990), The Memorial Symptom Assessment Scale (MSAS) (Portenoy, Thaler, et al., 1994) and The Perspective-Taking Tools (Long, 1990).

Despite the small sample size ( $n = 13$ ), significant findings were found that provide tentative support for the linkages as postulated in the Lazarus and Folkman’s (1984) theory among patient psychological distress, patient physical symptom experiences, and perceived empathic behaviors by informal caregivers. Recommendations for clinical practice and future research are made based on this study’s preliminary results.

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## CHAPTER ONE

### Statement of the Problem

#### *Introduction*

Ovarian cancer (OVCA) is the second most common type of gynecological cancer diagnosed in women and the most frequent cause of death from all gynecological cancers in North America (NCIC, 2006). Over 70% of ovarian cancers are diagnosed at stage III or stage IV, rendering a poor prognosis (Yawn, Barrette, & Wollan, 2004). According to the last recorded data for actual cases and deaths (NCIC, 2006) there were 2,271 new cases of ovarian cancer, and 1,457 deaths resulting from this disease in Canada and 90 new cases with 65 deaths in Manitoba. It is estimated that 2,300 Canadian women were diagnosed with ovarian cancer in 2006, and approximately 1,600 women died of this disease. In 2006, it is estimated that there were 90 new cases in Manitoba, and 60 deaths resulting from a diagnosis of ovarian cancer (NCIC, 2006). Although mortality from ovarian cancer has been slowly decreasing over the past decade, its often asymptomatic initial presentation, and late diagnosis, (Luce, Hassey & Holcomb, 2003) results in a five year survival rate of only 30% or less (Yawn et al., 2004).

It is widely recognized that patients with cancer experience symptoms related to the management and treatment of their disease, as well as from the disease itself (Boehmke, 2004). Physical symptom experience has been widely studied within the cancer population (Holmes & Eburn, 1989) and chronic illness states (O'Neil & Morrow, 2001). Often described as a silent killer of women (McCorkle, Pasacreta, & Tang, 2003), signs and symptoms relevant to ovarian cancer do not often become apparent until compression of structures adjacent to the ovaries occur, ascites develop, or there is

clinical evidence of metastatic disease (Luce et al., 2003 ). Although prognosis is generally poor at this stage (20% to 30% survival rate), there is a 70% to 90% survival rate in those with early detection (Luce et al., 2003).

Because ovarian cancer remains a leading cause of mortality for women, a diagnosis of ovarian cancer often results in psychological distress (Howell, Fitch, & Deane, 2003). Women with ovarian cancer may be particularly vulnerable to psychological distress due to factors such as ablative surgery which may harm body image, a high rate (30 to 50 %) of disease recurrence, and the unlikelihood of a curative treatment for those with recurrent ovarian cancer (Norton et al., 2005). Although there is evidence that women with ovarian cancer suffer from high levels of psychological distress (Kornblith et al., 1995; Norton et al., 2004; Norton et al., 2005; Portenoy, Kornblith, et al., 1994), the impact of ovarian cancer on psychosocial functioning is a relatively neglected area of research (Hipkins, Whitworth, Tarrier & Jayson, 2005).

Norton et al. (2004) conducted a descriptive, correlational study (N=143) aimed at examining the prevalence of psychological distress experienced by women with stage I to stage IV ovarian cancer who were undergoing treatment. These authors found that approximately one fifth of women reported moderate to severe levels of distress, and more than half of women reported high stress responses to their cancer and treatment. Furthermore, Norton et al. found that 60% of patients were not undergoing any treatment via mental health services or psychotropic medications, and concluded that the high prevalence of psychological distress and high stress responses to cancer in the ovarian cancer population should be carefully evaluated to determine whether treatment for these symptoms is warranted.

Although a relationship between psychological distress and physical symptom experience has been previously established (Kornblith et al., 1995; Norton et al., 2005), there remains great variability between the levels of psychological distress amongst patients. Norton et al. (2005) suggested that the relationship between psychological distress and physical symptom experience must be influenced by other factors, such as social support from family or friends. According to Manne et al. (2003), aversive or unsupportive reactions and interactions with family and friends can be an extremely important source of stress for individuals with cancer. It is recognized that many individuals who have been diagnosed and treated for cancer rely on informal caregivers (usually family or friends) for support to help them cope with their disease (Lee, Brennan, & Daly, 2001). However, those from whom the patient desires support may not respond in a manner that is helpful or supportive (Manne et al., 2003) and may exhibit unsupportive behaviors such as criticizing the patient's responses to their illness experience, avoidance of discussions about the cancer and its effects, physical avoidance of the patient (Manne, Taylor, Dougherty, & Kemeny, 1997) and minimization of the importance of issues pertinent to the cancer (Dakof & Taylor, 1990).

Hipkins et al. (2005) conducted a prospective study in women with ovarian cancer (N=63) in order to determine psychological distress (anxiety and depression) in the three month period after chemotherapy and to identify factors that may predict psychological morbidity. Patients were assessed for anxiety, depression, and stage of disease and their perception of emotional support. Results of this study indicated that women with ovarian cancer experienced clinically significant psychological morbidity. The stage of disease and patient's performance status were not associated with worse psychological outcomes.

Based on the results of this study, they concluded that social support and intrusive thoughts, rather than physical parameters are the principle determinants of psychological morbidity in ovarian cancer patients.

These findings appear to be substantiated by Norton et al. (2005) who conducted a cross-sectional study (n=143) aimed at examining the relationship between illness-related and interpersonal stress on psychological distress in ovarian cancer patients. These authors found that women who perceived a lack of supportive behavior from informal caregivers (family and friends) exhibited higher levels of psychological distress. This perceived lack of support may be due to a perceived lack of empathic behavior towards those experiencing the disease. The positive impact of empathy on patient outcomes has been recognized and documented (Reide-Ponte, 1992). Empathy is a form of coping and can be exhibited by empathic behavior, which includes efforts to perspective-take, characterized by the ability to successfully estimate how another person is feeling or thinking (O'Brien & DeLongis, 1990). According to Morse et al. (1992) empathic behavior has a significant effect on the meaning of illness, which can impact coping. Previous research suggests that individuals who use empathically based strategies in responding to others experience less physical and psychological distress than those who use less interpersonal strategies (Lee, Brennan, et al., 2001). It is recognized that cancer patients rely on informal caregivers to help them cope with their illness (Lee, Brennan, et al., 2001; Lobchuk & Degner, 2002). However, little research exists that examines the influence of empathy within the context of the informal care-giving relationship (Lee, Brennan, et al., 2001, Lobchuk, 2001). Norton et al. (2004) highlighted

the need to explore the relationship between patient's perceived informal caregiver behaviors and the psychological distress of ovarian cancer patients.

Norton et al. further suggested that more research is needed to address the research gap on the linkage between caregiver supportive behaviors, physical symptom experience, and psychological distress as well as to examine indicators of psychological distress beyond anxiety and depressive symptoms in the ovarian cancer population. Awareness of the role of empathic behaviors within the informal care-giving setting may provide additional information that can direct interventions (Lee, Brennan, et al., 2001).

### *Theoretical Perspective*

Overall this study was guided by the stress, appraisal, and coping theory developed by Lazarus and Folkman (1984), which was adapted to conceptualize the influence of social support and empathic behavior of "informal caregivers" on psychological distress and physical symptoms experience in ovarian cancer patients. This framework has been utilized extensively within healthcare literature to explain the relationships between stressful events and coping styles (Kramer, 1993; Lee, Brennan, et al., 2001; Zabalegui, 1999). This adapted model also included components of the Relationship-Focused Coping Strategies that were developed by O'Brien and Delongis (1990) and adapted from Lazarus and Folkman's (1984) model in order to promote understanding of coping outcomes influenced by empathic behavior (Figure 1).

According to Lazarus and Folkman (1984), when confronted with a stressor (physical symptom experience), an individual appraises the situation as either threatening, or benign, which ultimately influences how an individual will cope with the situation. This appraisal is influenced by personal and environmental resources. O'Brien

and Delongis (1990) proposed that relationship-focused coping strategies involving perspective-taking may be important with patients and family care-givers.

The focus on the social support (personal resource) component of Lazarus and Folkman's (1984) model attempted to at least partially explain the relationship among physical symptom experience, perceived empathic behavior of caregivers, and psychological distress. In the current study, the MSAS quantified physical symptoms experienced by ovarian cancer patients, the empathic behaviors by informal caregivers was quantified by the Perspective-Taking Tool, as well as the Empathic Responding Scale, and psychological distress was quantified by the Hospital Anxiety and Depression Scale. Guided by Lazarus and Folkman's (1984) model, it was determined to be plausible that when the patient perceives the informal caregiver does not engage in empathic behaviors, the patient's personal resources decrease and the physical symptom experience is appraised as more threatening. This can result in psychological distress.

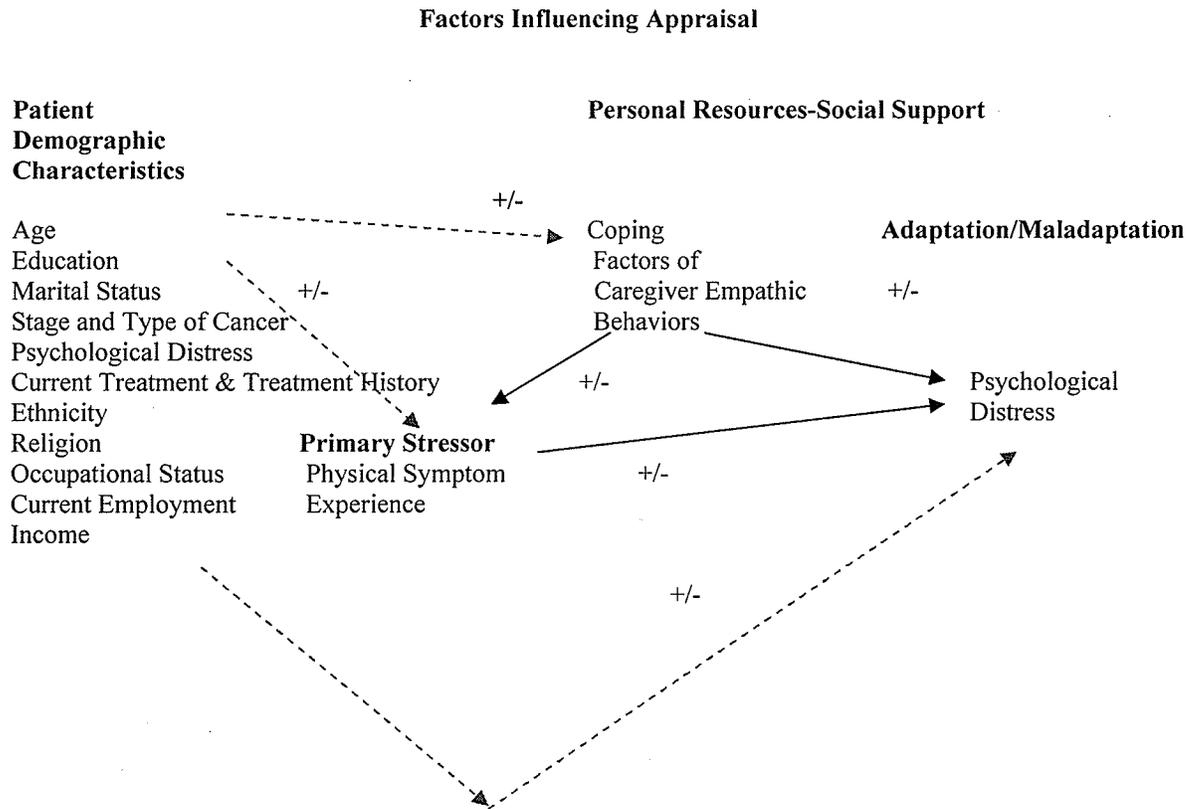
#### *Operational Definitions of the Research Variables*

In order to facilitate understanding of the research variables, the following definitions were established to provide clarity to the variables being measured in this pilot project.

##### *Empathic Behavior*

Empathic behavior can be defined as a multidimensional determinant of social behavior that drives caring and supportive actions between the patient and the informal caregiver. Empathic behavior involves efforts by the patient and informal caregiver to engage in perspective-taking in order to vicariously experience the world as the other person sees it and to formulate one's own associations to the symptom event. Empathic behaviors also involve patient's and caregiver's efforts to interpret the psychological states that underlie

Figure 1. Adapted Lazarus and Folkman (1984) model



Note: Solid black lines indicate the relationships of primary interest; dashed, grey lines indicate exploratory relationships

Model of Stress, Appraisal and Coping (Lazarus & Folkman, 1984) adapted to include perceived empathic informal caregiver behavior (O'Brien & Delongis, 1990).

the other person's verbal and non-verbal communication, and to respond sensitively to the other person out of a state of concern or to express caring or understanding in an accepting, nonjudgmental, emotionally validating manner (O'Brien & Delongis, 1990; p.783). The empathic behaviors in this study were explored within the context of perspective-taking activities as these are the underlying cognitive processes that drive empathic behaviors (O'Brien & Delongis, 1990).

#### *Physical Symptom Experience*

Physical symptom experience is defined as a multidimensional construct that involves numerous physical symptoms experienced by cancer patients with varying levels of frequency, severity, and distress. Physical symptom experience is viewed as a potential stressor that can impact patient's psychological distress (Portenoy, Thaler, et al., 1994).

#### *Psychological Distress*

Psychological distress has been defined as an unpleasant experience that can be of emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer. It extends along a continuum, and includes common normal feelings of vulnerability, sadness, and fears, to problems that are disabling such as true anxiety, depression, panic, and feelings of isolation or spiritual crisis (NCIC, 2006, p.10). The focus for this study was to assess anxiety and depression (as captured by the HADS; Zigmond & Snaith, 1983) as a measure of psychological distress.

#### *Research Questions*

The purpose of this study was to investigate the linkage between empathic informal caregiver behaviors, physical symptom experiences, and psychological distress

experienced by patients with Stage I- Stage IV ovarian cancer. The following questions were central to this pilot study:

- 1) What is the prevalence of empathic informal caregiver behaviors, physical symptom experience, and psychological distress in Stage I - Stage IV ovarian cancer patients?
- 2) Are there associations among empathic informal caregiver behaviors, patient physical symptom experiences, and patient psychological distress?
- 3) What is the concurrent validity of the Empathic Responding Scale (Delongis & O'Brien, 1990) compared with the Perspective-Taking Tool (Long, 1990)?

### *Significance*

The results of this study can have great significance for the care of patients with ovarian cancer and their informal caregivers. This study addresses an identified gap in the literature that speaks to the unexamined relationships between empathic informal caregiver behaviors and psychological distress. Highlighting the importance of the patient's perception of empathic behaviors by their informal caregiver as a contributor to physical symptom experience and psychological distress can have many implications. The incidence and prevalence of physical symptom experience and psychological distress can be decreased, resulting in fewer burdens in ovarian cancer patients, and the healthcare system. The results of this study could have future research implications where clinical interventions could then be developed and tested in order to reduce physical symptom experience and psychological distress of ovarian cancer patients.

## CHAPTER TWO

### Literature Review

#### *Introduction*

In order to facilitate understanding of the current state of the science in this area of research, a literature review was conducted. Three primary concepts of empathy, physical symptom experience, and psychological distress were the focus of this literature review. The purpose of this literature review was to identify knowledge relevant to these concepts as well as to examine the current research highlighting the linkages among perceived empathic behavior, symptom experience, and the psychological distress experienced by ovarian cancer patients. The following literature review is comprised of four sections which will include discussions under the headings of: 1) Ovarian cancer; 2) Physical symptom experience; 3) Psychological distress; and 4) Empathy.

#### *Ovarian Cancer*

Ovarian cancer is the second most frequently diagnosed gynecological cancer in North America and accounts for approximately 4% of all cancers in women (NCIC, 2006). Ovarian cancer accounts for more deaths per year than any other cancer of the female reproductive tract (Barnholtz-Sloan et al., 2003; NCIC, 2006). The high death to case ratio of ovarian cancer at 66% indicates a poor prognosis (poor prognosis is indicated by a ratio > 50%; NCIC, 2006).

According to Canadian Cancer Society Statistics (2006), the last recorded data for actual cases and deaths reported 2,271 new cases of ovarian cancer, and 1,457 deaths resulting from this disease in Canada, and 90 new cases with 65 deaths in Manitoba (NCIC, 2006). It is estimated that 2,300 Canadian women will be diagnosed with ovarian

cancer in 2006, and approximately 1,600 women will die of this disease. In 2006, it is projected that there will be 90 new cases in Manitoba, and 60 deaths resulting from a diagnosis of ovarian cancer. There are three main types of ovarian tumors, classified as follows: (a) Surface Epithelial Stromal Tumors, (b) Sex Cord Stromal Tumors, and (c) Germ Cell Tumors. Although these are the three major classifications, it should be noted that several combinations of subtypes exist under each of the major categories. The most common ovarian cancer, epithelial ovarian cancer rarely occurs in women below the age of 40, after which the incidence increases from 15 to 16 in 100,000 in the 40-44 years age group, to 57/100,000, and a peak rate, in the 70-74 year age group (Hoskins, Perez & Young, 1997).

Mortality from ovarian cancer has been slowly decreasing over the past decade. It's often asymptomatic initial presentation with vague gastrointestinal symptoms and weight gain in later stages, (Luce et al., 2003) resulting in 70% of women having Stage III or IV at the time of diagnosis (Fishman et al., 2005). Because of this, the five year survival rate is only 30% or less (Yawn et al., 2004).

#### *Epithelial Ovarian Tumors (EOTs)*

Epithelial ovarian tumors, which account for 60% of all ovarian tumors, and 90% of all malignant ovarian tumors (Harries & Gore, 2002), are more common in middle-aged and older women (Luce et al., 2003). Several types of EOTs exist. Some tumors are classified as benign if there is no cellular proliferation or invasion. Tumors are classified as borderline (also known as low malignant potential) if there is some cellular proliferation but no invasion. Because borderline tumors generally behave as benign tumors, they usually have a good prognosis (Luce et al., 2003). Malignant tumors are

those with invasive characteristics. It should be noted that malignant tumors can be further sub-classified into 5 major subtypes: serous, mucinous, endometrioid, clear cell, and transitional cell. Although these subtypes are helpful in evaluating tumor type, epithelial ovarian cancers are also assessed according to grade and stage. Grade 1 tumors are generally considered low grade, well-differentiated, and usually have a better prognosis. Grade 2 tumors are considered intermediate grade, moderately differentiated, and have a higher chance of metastasizing within the pelvic and abdominal area. Grade 3 tumors are considered high-grade, poorly differentiated, and are characterized by aggressive cancer cells with a high likelihood for metastasis, and generally have a poorer prognosis (Hoskins et al., 1997; Luce et al., 2003). Tumor Staging will be discussed in a subsequent section.

#### *Sex-Cord Stromal Tumors (SCSTs)*

These tumors develop from theca cells, other stromal cells, granulosa cells, sertoli and Leydig cells (Luce et al., 2003). SCSTs account for approximately seven percent of malignant tumors. More than half of these malignancies are found in women over 50 years of age. According to Luce et al. (2003) SCSTs may produce either male or female hormones, induce vaginal bleeding after menopause, and stimulate menstrual periods and breast development in young girls. Male hormone production can also disrupt normal menstrual function and stimulate facial and body hair.

#### *Germ Cell Tumors (GCT)*

GCTs develop from primordial germ cells, represent approximately three to seven percent of malignant ovarian tumors, and occur more frequently in young adults and children (Luce et al., 2003). There are a variety of malignant GCTs, including

teratoma, dysgerminoma, embryonal carcinoma, endodermal sinus, and chorio carcinoma.

Immature teratomas, which are extremely rare, occur in women who are younger than 18 years of age. Dysgerminomas represent only two percent of all ovarian cancers and usually affect women in their teens and 20's. When they are limited to the ovary, over 95% are cured by surgical excision of the ovary and do not usually require further treatment. Other types of GCTs include endodermal sinus tumor (yolk sac tumor) and choriocarcinoma occur rarely and typically affect young women (Hoskins et al., 1997). The following discussion will be confined to epithelial ovarian cancer as it represents approximately 90% of all ovarian malignancies.

#### *Risk Factors*

Although causative factors of ovarian cancers have not been identified (Tung et al., 2005), certain risk factors have been implicated in the development of ovarian cancer. Such risk factors include extensive lifetime ovarian stimulation resulting from ovulation, otherwise known as "incessant ovulation" (Hoskins et al., 1997; Luce et al., 2003). Incessant ovulation is hypothesized to increase the likelihood of recurrent ovarian epithelial cellular damage, with consequently abnormal DNA repair. Inactivation of tumor suppressor genes and other carcinogenic events resulting from incessant ovulation are also thought to increase the potential for malignant alterations (Tung et al., 2005). Thus, risk factors include advancing age, reproductive history, family history of ovarian cancer, and family or personal history of breast cancer (Luce et al., 2003). Although a history of ovarian cysts is not associated with an increased risk (Hartge et al., 2000), women with endometriosis are at an increased risk for clear cell ovarian cancer

(Modugno et al., 2004). Factors which may have protective properties include number of live births as well as long-term breast feeding, both of which suppress ovulation (Luce et al., 2003). Lifestyle factors such as smoking and a diet high in saturated fats have also been linked to an increased risk of ovarian cancer (Vergote & Trimbose, 2003). Empirical evidence is suggestive of an association between ovarian cancer and the consumption of red meat, pork, processed meats, and smoking (Luce et al., 2003).

### *Screening and Detection*

Although there have been advances in the development of treatment for ovarian cancer, a reliable screening method has yet to be identified. However, because of its often late diagnosis and consequent metastasis, early detection is essential for a positive outcome. Current modalities used for screening include bimanual rectovaginal examination, cancer antigen-125 blood test, and ultrasound (Tiffen & Mahon, 2005). However there is a lack of evidence supporting extensive population-based screening as current screening methods are unreliable and non-specific, have not reduced mortality or morbidity, and are costly (Tiffen & Mahon, 2005).

*Bimanual Rectovaginal Examination.* Physical examination occasionally reveals ovarian malignancy. However, the sensitivity and specificity of this examination have been reported as low in the detection of early ovarian cancer. Empirical evidence relevant to the specificity and sensitivity of rectovaginal examination in women with previously discovered pelvic masses have been reported at 67% and 96% (Andolf & Jorgensen, 1988).

*Cancer Antigen-125.* Although the serum tumor markers (including CA-125) have been expressed in 80% of epithelial ovarian cancers, it may also be increased in the

presence of other cancers. Thus, use of the CA-125 blood test should be used in response to chemotherapy.

*Ultrasound.* Although transvaginal or pelvic ultrasound has proven helpful in detecting advanced-stage ovarian cancer in asymptomatic women, (reported 98.1% specificity and 100% sensitivity), it has not shown as much potential in identifying early stage disease. Fishman et al. (2005) conducted a study aimed at determining the use of ultrasound evaluation in detecting early-stage epithelial ovarian cancer in asymptomatic, high risk women (N=4,526) and found that there was limited value of ultrasound evaluation (as an independent modality) in detecting early-stage epithelial ovarian cancer. The average cost estimate of transvaginal ultrasound evaluation has been reported at approximately \$250 (Tiffen & Mahon, 2005). Given that there is no single reliable screening method to detect ovarian cancer, multi-screening modalities are typically recommended for women at risk for this malignancy (Menon, 2004).

#### *Signs and Symptoms of Ovarian Cancer*

Ovarian cancer is often described as a “silent killer” of women (McCorkle et al., 2003). The signs and symptoms of ovarian cancer often do not become apparent until compression of structures adjacent to the ovaries occur, ascites develops, or there is clinical evidence of metastatic disease to the bowel (Luce et al., 2003 ). Although the prognosis is generally poor when metastasis is evident (20%-30%), there is a 70%-90% survival rate in those with early detection (Luce et al., 2003). Symptoms that have been associated with ovarian cancer include persistent and vague abdominal discomfort and/or pressure, bloating, enlargement of abdominal girth, unexplained weight gain, pelvic or low back pain, unexplained change in bowel or bladder habits, increased urinary

frequency and pain on intercourse. In a study conducted by Kirwan, Tincello, Herod, Frost, and Kingston (2002), it was found that 93% of women with ovarian cancer reported experiencing at least one symptom. However, because many of these symptoms are commonly experienced, patients and healthcare providers may not associate them with ovarian cancer (Yawn et al., 2004), and thus they may not be given adequate attention from the patient or healthcare provider.

### *Staging & Treatment*

Treatment of ovarian cancer involves the initiation of surgical intervention and/or chemotherapy, and usually commences with staging laparotomy to prove stage I which includes peritoneal washings or ascites aspiration for cytologic analysis, hysterectomy (removal of uterus), bilateral oophorectomy (removal of both ovaries), or total supracolic omentectomy with omental involvement, pelvic and para-aortic lymph node sampling, diaphragmatic biopsies, random biopsies of the peritoneum., and possible chemotherapy and/or radiotherapy (Hoskins et al., 1997; Vergote & Trimbose, 2003). In a study conducted by Vergote and Trimbose (2003) where they assessed treatment modalities in women with ovarian cancer, radiotherapy was associated with a higher incidence of distressing symptoms such as bowel obstruction. Cytoreductive surgery often consists of bowel resection if it aides tumor reduction, with the most common type being rectosigmoid colectomy (Hoffman et al., 2005).

The International Federation of Gynecology and Obstetrics (FIGO) staging system is used to stage ovarian cancer, ranging from Stage I to Stage IV, and is used to estimate level of risk for recurrence. The stage of ovarian cancer is defined as the extent of disease at the time of diagnosis, and can be determined only following exploratory

laparotomy and a thorough evaluation. According to The FIGO staging system for ovarian cancer, Stage I indicates growth limited to the ovaries, Stage II indicates growth involving one or both ovaries involving pelvic extension, Stage III indicates tumor involving one or both ovaries with peritoneal implants outside the pelvis and/or positive retroperitoneal or inguinal nodes, verified malignant extension to small bowel or omentum; Stage IV ovarian cancer indicates growth involving one or more ovaries with distant metastases. It should also be noted that Stages I to II ovarian cancers are also subclassified according to growth and extension of the tumor (Hoskins et al., 1997)

#### *Summary of Ovarian Cancer*

As ovarian cancer is associated with such a high mortality rate in comparison to other gynecological cancers, and is a leading cause of cancer-related death in women, early detection and treatment are essential (Yawn et al., 2004). Risk factors for ovarian cancer include incessant ovulation, family history of ovarian cancer, personal or family history of breast cancer, endometriosis, advancing age, hormone replacement therapy, and lifestyle factors such as increased dietary fat, and smoking. Factors thought to exert a protective effect against the development of ovarian cancer include long-term (8-10 years) oral contraceptive use, parity (the number of pregnancies) (Thomas, 1997), and extended breastfeeding (Luce et al., 2003). Although it has been widely assumed that the initial presentation of ovarian cancer is asymptomatic, evidence is suggestive of vague abdominal symptoms, which are not typically associated with this malignancy (McCorkle et al., 2003). Symptomatic presentation often becomes evident at Stage III and Stage IV disease and typically manifests as abdominal cramping, ascites, bowel obstruction, weight gain, and increased abdominal girth (Koldjeski, Kirkpatrick, Swanson, Everett, &

Brown, 2003). Treatment of epithelial ovarian cancer usually consists of surgical intervention with adjuvant chemotherapy. Extensive staging and cytological analysis are also conducted in order to determine risk of recurrence (Harries & Gore, 2002). Although survival rates for Stage III and Stage IV ovarian cancer remain poor at <30%, there is a 90% survival rate with early detection, thus highlighting the need for accurate screening (Koldjeski et al., 2003). Management and treatment of this disease should include physical as well as psychosocial factors in order to minimize distress-related complications.

### *Symptom Experience*

It is widely recognized that patients with cancer experience symptoms related to the management and treatment of their disease, as well as from the disease itself (Boehmke, 2004). The measurement of physical symptoms has been extensively explored in cancer literature (Larsen, Nordstrom, Ljungman & Gardulf, 2004). The accurate and concise measurement of patient's symptom experiences is important, particularly in the cancer population as it may highlight areas of need pertinent to interventions (Richer & Ezer, 2000).

Rhodes and Watson (1987) acknowledged the significance of symptom experience and recognized that this concept was ill-defined. They defined *symptoms* as phenomena which are perceived by an individual as a characteristic of a condition that indicates a deviation of normal function, sensation, or appearance (p. 242). Although there are varying components to the above definitions, it is commonly accepted that symptoms are highly subjective, and thus manifest themselves in a variety of ways. Kristjanson et al. (1998) stated that the potential for symptoms to be perceived differently

by patients and family members may result in inappropriate management with resulting poor outcomes (p. 24).

McDaniel and Rhodes (1995) described symptom experience as involving the perception of the frequency, intensity, distress, and meaning occurring as symptoms are produced and expressed. According to McDaniel and Rhodes (1995), symptom experience includes both situational and existential meanings of individual symptoms as well as the combined impact of multiple symptoms. Rhodes, Watson, Johnson, Madesen, and Beck (1987) identified that symptom experience is comprised of symptom occurrence (cognitive) and symptom distress (emotive) which arise from symptoms.

#### *Components of Symptom Experience*

*Symptom Occurrence.* Symptom occurrence is the cognitive component of the symptom experience and refers to the way subjective information surrounding the symptom is perceived and includes underlying dimensions of frequency, severity and duration (Lenz, Suppe, Gift, Pugh, & Milligan, 1997; Rhodes et al., 1987). Symptom occurrence is further described as a stressor that initiates the simultaneous response of fear behaviors (Rhodes & Watson, 1987). Armstrong (2003) used this conceptualization and defined symptom occurrence as a phenomena used to recognize that symptoms rarely occur in isolation, and that symptoms often influence and are influenced by the occurrence and attributes of other symptoms, and consist of intensity, duration, and frequency.

*Symptom Distress.* Symptom distress or the emotive response to the cognitive component of symptom experience has been defined as the individual's awareness and ability to recognize the degree of physical or mental anguish arising from the symptom

experience (Rhodes et al., 1987). Symptom distress is the emotional dimension of symptom experience and refers to how the symptom makes the individual feel emotionally, rather than how it severely or frequently it is experienced. Rhodes and Watson (1987) describe symptom distress as a manifestation of the level of physical or mental upset, anguish, or suffering experienced from a specific symptom. Symptom distress is highly subjective in nature, for example, a symptom that may cause distress for one person may not cause distress for another. This variance is also influenced by the meaning of the symptom event that is being experienced (Woodgate & McClement, 1998), which speaks to the multi-dimensional impact of the family support system.

As actual symptoms may vary across the cancer population, the understanding of what the symptoms represent is also highly subjective. The meanings placed upon symptoms are thought to determine level of intervention necessary (Richer & Ezer, 2000). According to McDaniel and Rhodes (1995) personal meaning relevant to physical symptoms may significantly impact physical and psychological well-being, and thus impact an individual's quality of life. Perception of a symptom may be influenced by its attributed meaning, regardless of its frequency of occurrence, and consequently result in added distress. The concept of meaning is complex and is comprised of situational and existential factors, which are then influenced by positive or negative attributions (Richer, & Ezer, 2000). A patient's perception of the impact of a particular symptom on her daily life is considered situational. Such meaning may be initiated by the inability to continue with ordinary tasks. A cancer patient may be unable to wash dishes due to extreme fatigue resulting from treatment, thus impacting her daily life. Existential meanings stem from an individual's perception of reality and deal with feelings of mortality or

helplessness resulting from symptoms which remind him/her of the illness. The experience of fatigue may remind a cancer patient of her disease and perhaps impending mortality. Alternatively, positive meaning could be attributed to the experience of fatigue where a patient may perceive the experience of fatigue as proof of success of treatment. Thus, the subjective meanings attributed to a particular symptom may not be the most distressing symptom (Armstrong, 2003). A diagnosis of ovarian cancer is characterized by unique and specific factors that alter the meaning of quality of life and cancer survivorship, including a threat to femininity, statistically poor prognoses, and the feeling of having a “minority” cancer as it is frequently overshadowed by breast cancer and other cancers (Ferrel, Smith, Juarez, & Melanon, 2003).

Howell et al. (2003) conducted a qualitative study (N=18) regarding women’s experiences with recurrent ovarian cancer and concluded that implications for nursing practice involve understanding the significance of associated meaning in order to facilitate supportive communication as well as providing appropriate resources for management. In order to understand the significance of associated meaning it is necessary to recognize that the family often plays a substantial role regarding the interpretation of symptom experiences (Lobchuk & Stymeist, 1999). Patients and families construct meanings for symptoms based on the family’s distinct socially derived perceptions which stem from a broader cultural and ethnic set of meanings. This is particularly important as the family’s shared meaning of illness is manifested in how family members experience illness emotionally and how they behave within the context of the illness experience. For example, a particular family may emotionally react to a particular symptom event by viewing it as a “punishment”, and eventually begin to

behave with the patient in terms of the particular symptom rather than the individual who is experiencing them (Lobchuk & Stymeist, 1999). Accordingly, if the family member does not make attempts to engage in empathic responding (perspective-taking), the patient may feel misunderstood, resulting in psychological distress.

Thus, regardless of how well informed a patient is, they will still attach meaning to an experience based on previous experiences, beliefs and values, family, and cultural background (Luker, Beaver, Leinster, & Owens 1996). Consequently, it is incumbent upon nurses and healthcare providers to be aware of the importance of empathic responding within the informal caregiving context in order to promote positive adaptive responses to the illness experience.

There have been many attempts to utilize the concept of symptom distress (Boehmke & Brown, 2005; Manning-Walsh, 2005), most of which appear to concur with the definition formulated by Rhodes et al. (1987). Throughout the literature, symptoms are associated with the manifestation of disease, and symptom distress is used to describe the subjective experience of people in various states of health and illness (Goodell & Nail, 2005). Johnson (1999) described symptom distress as being comprised of physiologic and reactive components and utilized this conceptualization of symptoms in her theory of self-regulation.

The conceptualization of symptom experience (including occurrence and distress) delineated by Rhodes et al. (1987) appears to concur with The University of California, San Francisco School of Nursing Symptom Management Faculty Group [UCSF] (1994) description of symptom experience as being a dynamic process, involving the perception, evaluation and meaning of, and response to a symptom. Portenoy, Thaler, et al. (1994)

developed the Memorial Symptom Assessment Scale (MSAS) in order to quantify the multi-faceted nature of symptom experience of a mixed group of cancer patients (N=246). Portenoy, Thaler, et al. (1994) also recognized the complexity of symptom experience in their description of it as a multidimensional construct that involves numerous physical and psychological symptoms experienced by cancer patients with varying levels of frequency, severity, and distress. They also viewed symptom experience as a potential stressor that can impact a patient's psychological distress.

Lobchuk and Degner (2002) conducted a study involving advanced stage cancer patients and their family caregivers (N=98) to compare their perceptions of patient's multidimensional symptom experiences based on presence, frequency, severity, and distress as captured on the MSAS in order to determine perceptual accuracy. These authors concluded that although family caregivers can provide reasonable proxy or complementary reports on patient's symptom experiences of frequency, severity, and distress, family members experienced greater difficulty in attaining high levels of accuracy on psychological versus physical symptoms. Lobchuk and Degner's study results showed that family caregivers tended to overestimate patient's symptom experiences and that their bias to over-report was greater on psychological versus physical symptoms. These authors suggested that this bias to overestimate on psychological symptoms might be due to caregivers who projected their own emotions onto their estimate of patient's worrying. On the other hand, caregivers in Lobchuk and Degner's (2002) study appeared to engage in patient-oriented thinking that resulted in caregiver estimates that were more closely aligned with patient's self-reports on physical versus psychological symptom events.

### *Symptom Experience and Ovarian Cancer*

Although the phenomenon of symptom experience (including the sub dimensions of symptom occurrence and symptom distress) has been widely studied within the cancer population (Holmes & Eburn, 1989) and chronic illness states (O'Neil & Morrow, 2001), limited information involving symptom experience and ovarian cancer was found. Portenoy, Kornblith, et al. (1994) recognized the detrimental impact that unresolved symptoms have on quality of life and conducted a study involving ovarian cancer patients (N=151) in order to characterize pain and other symptoms in the ovarian cancer population. The authors of this study reported that pain, fatigue, and psychological distress were prevalent symptoms, with greater than 40% of ovarian cancer patients experiencing pain that substantially undermined their functional status and contributed to psychological distress. Portenoy, Kornblith, et al. also reported that compared to patients without pain, those who experienced pain reported significantly higher levels of psychological distress and lower scores on a measure of global quality of life. This is significant because those patients who lacked supportive relationships (unmarried status) experienced more pain (physical symptom experience), which resulted in psychological distress.

### *Measuring Symptom Experience*

A variety of tools have been developed in the attempt to quantify the multidimensional symptom experience through occurrence, and distress (Portenoy, Thaler, et al., 1994). The following section represents evaluation of instruments aimed at quantifying psychological distress.

*The Adapted Symptom Distress Scale (ASDS-2).* The ASDS-2 was developed by Rhodes, McDaniel, Homan, Johnson and Madsen (2000) which they adapted from the Symptom Distress Scale (SDS) that was originally developed by McCorkle and Young (1978). The original SDS was developed to measure symptom distress in cancer patients (N=26) by identifying concerns of patients receiving active cancer treatments. This instrument identifies 13 symptoms including nausea (frequency and intensity), appetite, insomnia, fatigue, pain (frequency and intensity), breathing, cough, mobility, bowel pattern, mood, concentration, appearance and outlook (McCorkle & Young, 1978). Although the SDS reported high reliability and validity with reliability coefficient alpha .82 and standardized alpha at .83, it does not include symptoms that may be prevalent in cancer patients such as vomiting, nor does it distinguish between symptom occurrence and distress (Rhodes et al., 2000). The ASDS-2 was developed in an effort to quantify the distinct components of symptom experience.

The ASDS-2 is a 31 item, 5-point Likert-type self report instrument that provides a total symptom experience score. The ASDS-2 was developed to assess 14 symptoms that are categorized into six symptom experience subscales: gastrointestinal problems, pain/discomfort, respiratory problems, fatigue/restlessness, concentration, and appearance (Rhodes et al., 2000). Reliability and validity were tested in a convenience sample of chronically ill and cancer patients (N=354). Internal consistency using Cronbach's alpha was reported as 0.91 for the total experience score, 0.76 for total distress, and 0.90 for total occurrence. The ASDS-2 was analyzed for validity using the Kruskal-Wallis test and was determined to be valid as the symptom experience score differentiated between well persons and individuals with cancer in all age groups. According to Rhodes et al.

(2000), although the ASDS-2 has demonstrated adequate psychometric properties, further testing is necessary with a variety of patient populations and in a variety of settings.

Boehmke (2004) conducted a study in breast cancer patients (N=120) to determine whether the SDS or ASDS-2 was a more accurate measure of symptom assessment and noted that several items in the ASDS-2 are measured multiple times including the item nausea (measured 8 times), thus adding to the length of the tool. The results of this study reported high correlation between both instruments, identifying a possible question as to the requirement of the ASDS-2. Additionally, it was noted that although the ASDS incorporates symptom intensity and frequency, it does not take into consideration multidimensional assessments including personal appraisal and social support (Boehmke, 2004). Boehmke also found that only 11% of participants preferred the ASDS-2 due to issues of confusion regarding wording, ease of completion and length of the instrument. Results of this study indicate that this tool may be confusing and burdensome for patients to complete.

*Symptom Experience Scale (SES)*. The SES was developed by Samarel, et al. (1996) in order to measure women's experiences of symptoms associated with treatment for breast cancer. The SES is also a modification of McCorkle and Young's (1978) Symptom Distress Scale (SDS) and was developed and tested in a sample of women with breast cancer (N=252) based on the concern that the SDS does not permit separate measurement of the frequency, intensity, and distress for each symptom (Samarel et al., 1996). The SES measures the frequency and intensity of breast-cancer related symptoms and the resulting distress experienced from them. The SES consists of 24 items measuring 8 symptoms on a 5-point Likert-type scale designed to capture frequency,

severity, and distress. Cronbach's alpha coefficients were reported as ranging from 0.92 to 0.96, indicating a high level of reliability. However, reliability and applicability for the use of the SES with a variety of populations and in a variety of settings has not been established (Lobchuk, 2001, Samarel et al., 1996), therefore the appropriateness of the SES with the ovarian cancer population cannot be verified.

*The Rotterdam Symptom Checklist (RSC).* The RSC is a 31 item scale that was designed to measure the existence of both physical and psychological symptoms of cancer patients who participated in clinical research (Cleeland et al., 2000). The extent to which a particular symptom was bothersome to a patient is self-assessed over the past 3 days or past week, and is rated on a four point scale from "not at all" to "very much." Validity and reliability for this tool are reported as high (Hardy, Edmonds, Turner, Rees, & Hern, 1999), and it has been cited as simple, quick, discriminatory, and easily understandable (Lobchuk, 2001). However, limitations regarding its use in a variety of cancer patient populations have also been cited (Hardy et al., 1999; Stein et al., 2003). For instance, although the RSC was developed and tested in a sample consisting primarily of breast and ovarian cancer patients, it does not include "bloating" or "weight gain" (Stein et al., 2003), both of which are symptoms associated with ovarian cancer (Hoskins et al., 1997; Luce et al., 2003). Stein et al. (2003) had concerns as to whether this tool would be appropriate for a variety of cancer patient populations. This led the authors to modify this checklist and rename it as The Modified Rotterdam Symptom Checklist (RSCL-M). The RSCL-M was developed to include symptoms that were excluded in the original checklist such as weight loss, weight gain, problems controlling urination, problems controlling bowels, and cough. Although the RSCL-M includes

symptoms that would provide for more comprehensive evaluation of the frequency and occurrence of symptoms; it neglects to take into account measures of symptom distress. As symptom distress has been cited as a crucial component of symptom experience (Rhodes et al., 1987), this tool appears to be inappropriate for the measurement of the multidimensional nature symptom experience.

*The Memorial Symptom Assessment Scale (MSAS).* The MSAS was developed by Portenoy, Thaler, et al. (1994) to evaluate the multidimensional experience about a diverse group of symptoms. This 32 item instrument assesses the frequency, severity, and distress of physical and psychological symptoms based on separate 5-point Likert-type scales. Portenoy, Thaler, et al. developed the MSAS as a tool that captures the multidimensional symptom experience, including distress and occurrence items. These authors also found evidence to support that symptom experiences are a fundamental component of quality of life. The MSAS is a reliable and valid instrument for the assessment of symptom prevalence, characteristics, and distress, and provides a comprehensive assessment of symptoms. Although the length and multiple ratings that are required for each symptom have been cited as cumbersome (Cleeland et al., 2000), its use and reliability in both cancer and non-cancer populations have been consistently reported. Tranmer et al. (2003) conducted a study in a cohort of seriously ill cancer and non-cancer hospitalized patients near the end of life (N=135) in order to determine if use of the MSAS is valid for all populations and reported internal consistencies from 0.77 to 0.85. Tranmer et al. (2003) concluded that the MSAS appears to be a reliable way to assess symptoms in patients with and without cancer. Additionally, it should be noted that the MSAS was not only developed in a heterogeneous group of cancer patients

(Portenoy, Thaler, et al., 1994), but also utilized in a separate study that assessed the symptom experiences of ovarian cancer patients (N=151). These authors concluded that the data provided by the MSAS not only demonstrated the diversity of symptoms experienced by patients with ovarian cancer, but confirmed prevalence rates for certain symptoms that may contribute to a decrease in quality of life. As the MSAS has been established as a reliable and valid tool for use with ovarian cancer patients for assessing symptom experience, the investigator deemed the MSAS to be appropriate for use in this pilot study.

### *Psychological Distress*

The concept of psychological distress has been the focus of healthcare research for decades (Baer, Davitz & Lieb, 1970; Holmes & Eburn, 1989; Lazarus & Folkman, 1984; Ridner, 2004), and its prevention and treatment has been recognized as a phenomenon of consequence in the provision of quality patient care (Holmes & Eburn, 1989; Ridner, 2004). The term *psychological distress* has been used in a variety of contexts that focus on life prolongation and relief of suffering (Holmes & Eburn, 1989). However, ambiguity remains regarding its actual definition within the realm of healthcare. This ambiguity stems from inconsistent use of the term *psychological distress* to describe a variety of patient conditions (Ridner, 2004), which has been identified as being detrimental to the provision of quality healthcare. This detriment is due to inconsistent assessment and recognition, resulting in inconsistent or lack of treatment (Johnson, 1999). Accordingly, in order to successfully quantify psychological distress, conceptual clarification regarding the use of this term within the context of healthcare is required.

*Psychological Distress in HealthCare Literature*

Research literature on psychological distress has provided valuable data that is significant to the experience of cancer patients (Kelly & Caldwell, 2002). However, due to the subjectivity of psychological experiences, it has been difficult to quantify psychological distress (Karasz, Sacajiu, & Garcia, 2003). Throughout the literature, psychological distress has been associated with uncertainty (Provencher, Perreault, St.Onge, & Rousseau, 2003), maladaptation (Nolen-Hoxsima et al., 1997), physical and emotional torture (Saab et al., 2003), exhaustion, strain, weakened nerves (Provencher et al., 2003), depleted condition (Saab, et al., 2003), vulnerability (Hemenover, 2003), and mental anguish resulting from past or present situations (Ridner, 2004). Concepts that have been identified as being influential factors or outcomes of psychological distress include pain (Copp, 1974; Portenoy, Thaler, et al., 1994), coping (Manne, Glassman & Du Hamel, 2000; Hipkins et al., 2005) and quality of life (Howell et al., 2003; Laubmeier & Zakowski, 2004).

Psychological distress is a concept that is used inconsistently in healthcare literature in light of its varied conceptualizations. Although there are a variety of concepts associated with psychological distress, the actual term is defined inconsistently. Healthcare literature has captured psychological distress in relation to impairment of quality of life and altered coping by cancer patients (De Ridder, & Schreurs, 2001; Hipkins et al., 2005; Laubmeier & Zakowski, 2004; Nordin, Berglund, Glimelius, & Sjoden, 2001; Sneeuw, Aaronson, de Haan, & Limburg, 1997; Sneeuw, Sprangers, & Aaronson, 2002).

Investigators in the cancer population commonly operationalize psychological distress as depression and anxiety (Ahlberg, Ekman, & Gaston-Johansson, 2005; Hipkins et al., 2005; Laubmeier & Zakowski, 2004; Nordin et al., 2001; Petersen & Quinlivan, 2002; Smith, Gomm & Dickens, 2003; Twillman & Manetto, 1998). Existing literature described the identification and reduction of psychological distress experienced by patients (Ridner, 2004) as having a positive effect on the adjustment to a cancer diagnosis (Ferrell, 1993) and decreasing physical symptoms such as pain (Copp, 1974). The reduction of psychological distress is also thought to facilitate a therapeutic relationship with healthcare professionals (Kahn, 1986).

#### *Psychological Distress in Cancer*

Psychological distress as a result of diagnosis, management, and prognosis of cancer has been well documented (Herschbach et al., 2004; Kelly & Caldwell, 2002). There is general agreement that distress from illness can span both physical and psychological domains and have a substantial impact on quality of life (Baer et al., 1970). This is particularly applicable relevant to the cancer population (Yan & Sellick, 2004). The cancer patient must adapt to physical and psychological alterations stemming from the disease and its treatment (McCorkle et al., 2003). Consequently, the complexity of issues related to cancer can cause severe impairment in quality of life (McMillan & Small, 2002). Quality of life has been recognized as a key indicator of effectiveness of cancer treatment and care (Yan & Sellick, 2004), and has been identified as having an inverse relationship with psychological distress (Graham & Longman, 1987; Portenoy, Thaler, et al., 1994). Although a certain amount of psychological distress may be perceived as normal following a cancer diagnosis (Yarbro, Frogge, & Goodman, 2004),

its prevalence within the cancer population has prompted the development of widespread concern regarding its appropriate assessment and management (Larouche & Edgar, 2004).

Jefferies (2002) recognized that psychological distress in ovarian cancer patients was prevalent and that emotional and social support is extremely important due to their positive effects on quality of life and the reduction of distress. This finding has been supported by other studies, where investigators reported that a lack of social support is a significant risk factor in the development of psychological distress (Hipkins et al., 2005; Nordin et al., 2001),

According to Zabora, Brintzenhofesoc, Curbow, Hooker, and Piantadosi (2001), a patient's cancer experience is significantly impacted by psychosocial support. Zabora, et al. (2001) postulated that this important as most patients derive critical support from their spouses in order to problem-solve as well as to develop a buffer against the multiple sources of stress resulting from a cancer diagnosis. Psychological distress has an inverse relationship with social support and can stem from or result in increased physical symptoms such as pain (Portenoy, Thaler, et al., 1994), leading to ineffective coping (Norton et al., 2005). According to a study conducted by Manning-Walsh (2005) who examined the relationships between distress and quality of life in women with breast cancer (N=100), social support from family members and friends helped to decrease the negative effect of psychological symptoms on quality of life.

McCorkle et al. (2003) evaluated literature involving the psychological distress experienced by women with ovarian cancer and concluded that psychiatric morbidity may be particularly significant to outcomes and highlighted a need to clarify psychiatric

phenomena with these patients. This being stated, it would be useful to examine the prevalence of this phenomena within the ovarian cancer population. According to Norton et al. (2004), 20% of women with ovarian cancer (N=143) reported high stress levels in response to their cancer and treatment, and that more than 60% were not receiving any type of psychological treatment. These investigators reported that when patients perceived a lack of social support they experienced higher levels of distress than patients who perceived social support. Norton et al. (2004) concluded that when patients perceived lack of supportive behavior from caregivers it posed a significant risk factor for the development of psychological distress. This is substantiated by Hipkins et al. (2005) who reported that the perception of a lack of social support is primary risk factor for the development of psychological distress and reduced quality of life in ovarian cancer patients. The identification and treatment of psychological distress is particularly important in the ovarian cancer population. According to Zabora et al. (2001), failure to detect and treat elevated levels of psychological distress jeopardizes the outcomes of cancer therapies, decreases patient's quality of life, and increases healthcare costs. Psychosocial screening with prospective interventions is a necessary component of comprehensive cancer care.

#### *Conceptual Clarification of Psychological Distress.*

Distress can be considered a part of the human experience and has been studied for decades. The noted physician Hans Selye (1956) defined distress as "harmful and unpleasant stress" (p.138), resulting from the appraisal of a stressor as threatening, and the subsequent inability to effectively cope with the situation. As the appraisal of a situation and subsequent ineffective coping takes place within the psychological realm,

the term psychological distress appears to have evolved from Selye's (1956) definition. The psychologists Lazarus and Folkman (1984) appeared to utilize Selye's definition in their framework entitled *Stress, Appraisal and Coping*. According to this model, psychological distress results from an individual's interpretation (appraisal) of a threatening stressor, and is more strongly associated to social support among cancer patients rather than objective disease characteristics (Lee, Ku, Dow, & Pai, 2001).

Ridner (2004) conceptually analyzed psychological distress and defined it as "the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person" (p.539). This is also consistent with the definition formulated by The National Comprehensive Cancer Network (2005) where psychological distress is defined as "an unpleasant experience of emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer" (p.10). The NCCN (2005) further postulated that psychological distress extends along a continuum, and includes common normal feelings of vulnerability, sadness, and fears, to problems that are disabling including true anxiety, depression, panic, and feelings of isolation or spiritual crisis" (NCCN, 2005, p.10).

As this study involved patients who were diagnosed with cancer, and since the NCCN's (2005) definition of psychological distress has been utilized in the cancer population, for the purposes of this pilot study, psychological distress is defined as a multi-dimensional construct that can be sub-divided into dimensions of depression (involving feelings of sadness and isolation) and anxiety (involving excessive worrying and panic) (NCIC, 2006).

### *Components of Psychological Distress*

*Depression.* Depression has been defined as a mentally or emotionally disruptive condition that occurs in response to adverse external influences, and is capable of affecting physical health (Thomas, 1997). Depression resulting from a diagnosis of cancer can interfere with treatment, increase length of hospital stay, reduce a person's ability to care for him or herself, impair quality of life, and possibly reduce overall survival time (Goodwin, Zhang, & Ostir, 2004). Patients with a diagnosis of cancer are at an increased risk of having depression (Smith et al., 2003). Cancer-related depression has been described as a pathologic affective response to a loss of normalcy and certainty of one's personal world because of a cancer diagnosis, treatment, or impending complications. Cancer-related depression is similar to grief in that it is manifested by feelings of sadness, tearfulness, and yearning for the loss object (Lovejoy & Matteis, 1997). According to Lovejoy and Matteis (1997), cancer-related depression has also been associated with fears of death, abandonment, loss of social value, and financial dependence. Although there are physical manifestations of depression, including weakness, lethargy, headaches, backaches, insomnia, these are unreliable symptoms that may mimic symptoms of cancer (Lovejoy & Matteis, 1997).

*Anxiety.* Anxiety has been defined as a vague apprehension, worry, uneasiness, or dread resulting from an often non-specific source. Anxiety is the normal reaction to anything that threatens ones' body, lifestyle, and values or loved ones (Thomas, 1997, p.127). Although a certain amount of anxiety is normal, excess anxiety may interfere with functioning and has a negative effect on quality of life that persists over time (Schreier & Williams, 2004).

According to Stark and House (2000) anxiety is common in cancer patient populations because the diagnosis of cancer is threatening. Somatic manifestations of anxiety include symptoms of autonomic hyperactivity as such as palpitations and perspiration, as well as physical symptoms of muscle tension and fatigue. According to Stark and House (2000) anxious behaviors are characterized by restlessness, apprehension, worry and poor concentration and must be recognized by healthcare professionals in order to determine level of intervention necessary.

The prevalence of anxiety and depression in patients with epithelial ovarian cancer (N=246) were measured by Bodurka-Bevers et al. (2000). Depression was measured with the Center for Epidemiologic Studies-Depression (CES-D) and anxiety was measured by the State Anxiety Subscale of the Spielberger State-Trait Anxiety Inventory. The investigators of this study reported that 21% of patients met the CES-D criteria for clinical evaluation of depression, and 29% scored above the 75<sup>th</sup> percentile for anxiety (Bodurka-Bevers et al., 2000). According to Bodurka-Bevers et al. (2000) performance status was related to depression and anxiety as well as quality of life. Based on the results of this study, they concluded that clinically significant depression and anxiety may be more prevalent in this population than suspected and that screening and treatment of psychological distress should be initiated in order to improve quality of life. These findings are consistent with results reported by Hipkins et al. (2005) who conducted a prospective study in order to determine levels of anxiety and depression in ovarian cancer patients (N=63) and reported that ovarian cancer patients suffered from clinically significant levels of anxiety and depression. Hipkins et al. (2005) also concluded that social support rather than physical status were predictive of psychological

distress in this population, and that future research should always include measurement of perceived social support.

#### *Factors that Influence Psychological Distress*

*Pain.* According to Montes-Sandoval (1999), pain is a universal phenomenon that is deeply embedded within the human experience. Zimmerman, Story, Gaston-Johansson, and Rowles (1996) described pain as a psychological event that involves nociception, pain perception, and pain expression. *The American Heritage Dictionary of The English Language* (1996) defined pain as “an unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder” (p.1301). The concept of pain has been defined by the International Association for the Study of Pain as “an unpleasant sensory and emotional experience arising from actual or potential tissue damage or described in terms of such damage” (Thomas, 1997, p.1387). Healthcare literature describes the concept of pain as “whatever the patient says it is” (Montes-Sandoval, 1999; Thomas, 1997).

Zimmerman et al. (1996) identified that cancer pain is comprised of physiologic and sensory components. The physiological component of cancer pain includes the organic causes of pain such as bone metastasis, nerve compression, and tissue or organ infiltration. The physiologic component of pain is also related to type of pain (acute or chronic), the pattern of pain (transient, intermittent, or continuous) and whether it results from tumor, treatment, or is unrelated to the cancer. The sensory component of pain is comprised of the location, intensity, and perception of the pain (Zimmerman et al., 1996).

Associations between unrelieved pain and psychological distress have been consistently reported (Kornblith et al., 1995; Portenoy, Thaler, et al., 1994; Zimmerman

et al., 1996). Pain has not only been implicated in the development and exacerbation of psychological distress but also as a result of unrelieved psychological distress (Zimmerman et al., 1996). Georgesen and Dungan (1996) studied pain in patients with advanced cancer by analyzing four case studies and concluded that unresolved pain leads to suffering and spiritual, symptom, and psychological distress. The concept of pain is particularly relevant to healthcare professionals, who aim to restore equilibrium to the mental and physical health of patients.

Portenoy, Thaler, et al. (1994) conducted a study in order to determine the prevalence of pain in ovarian cancer patients (N=151) and concluded that among patients with ovarian cancer, greater than 40% experienced pain that substantially impacted function in one half to two thirds of patients. Portenoy, Thaler, et al. (1994) also reported that compared to patients without pain, those patients who experienced pain had significantly higher scores on a measure of psychological distress and significantly lower scores on a measure of global quality of life. Kornblith et al. (1995) also conducted a prospective study aimed at determining the nature and extent of pain and other physical problems, and psychological distress experienced by women with ovarian cancer (N=151). These authors reported that women who experienced high levels of pain and other physical symptoms experienced high levels of distress and low quality of life scores as measured by the Functional Living Index-Cancer (FLIC).

*Coping.* To cope is to “contend with difficulties and to strive to overcome them” (Soukanov, 1996, p. 414). Coping is defined in medical literature as “the use of resourcefulness and ability to deal with the stress of daily life and unusual challenges posed by chronic disease, disability, and pain” (Thomas, 1997, p.441). The psychologists

Lazarus and Folkman (1984) studied the impact of coping on stressful life events and defined coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141).

Coping is a phenomenon that is essential for maintaining mental and physical health (Yates, 1999). The concept of coping has particular relevance to nursing as alterations in patient environments may pose as threats that impact patient outcomes and quality of life (Donovan, Sanson-Fisher, & Redman, 1989; McMillan, 1996), and lead to ineffective coping, described as “impairment of adaptive behaviors and abilities of a person in meeting life’s demands and roles” (Thomas, 1997, p.441). Coping strategies have been described as “efforts to manage stressors” (Zabalegui, 1999, p.1511). Coping strategies identified by Lazarus and Folkman included the establishment of personal interactions (by seeking and using social support), attempting to perceive the problem objectively (distancing) and maintaining a constructive attitude (focusing on the positive), or by using physical (behavioral escape-avoidance) or mental (cognitive escape-avoidance) efforts to evade confronting the stressor. Patients with cancer often use a variety of these strategies to deal with their disease (Zabalegui, 1999).

Dragaset and Lindstrom (2003) conducted a study involving women with breast cancer, coping strategies and effects on mental health. They found that all coping strategies are not equal in terms of successful adjustment to disease. They found that women who self-reported as engaging in emotion-focused coping and sought social support facilitated opportunity for extra care. Alternatively, patients who engaged in physical or mental escape-avoidance strategies did not cope well and often sought

medical attention at a late stage, thus having an impact on their mental health. Dragaset and Lindstrom (2003) concluded that along with holistic care, a patient's mental health may have a substantial impact on their physiological condition. This conclusion was supported by Andersen, Kiecolt-Glaser, and Glaser (1994), who analyzed data from patients with cancer as well as healthy individuals and found that psychological (stressors) and behavioral (coping strategies) may have important health consequences by moderating the effects of the immune system. Stowell, Kiecolt-Glaser, and Glaser (2001) also conducted a cross-sectional study on the perception of stress based on coping ability and its effects on cellular immunity, and found evidence to support that relationships between coping methods and immune function depend on perception of stress.

Based on Lazarus and Folkman's (1984) model, O'Brien and Delongis (1990) identified three strategies of coping responses that include problem-focused, emotion-focused, and relationship-focused coping. O'Brien and Delongis (1990) suggested that interpersonal factors may influence every aspect of the stress and coping process, including the occurrence and appraisal of events as, well as the selection and efficacy of coping strategies. Problem-focused coping involves planning, problem solving and instrumental action and are used more for work stressors than interpersonal stressors (O'Brien & Delongis, 1990). Emotion-focused coping involves coping strategies aimed at managing the negative emotions that are associated with the stressor. Relationship-focused coping involves coping efforts that are aimed at maintaining an interpersonal regulation of relationships. According to O'Brien and Delongis (1990), positive relationship-focused coping strategies (empathic responding) are potentially important in the management and resolution of interpersonal stressors, and a lack of empathic

responding may contribute to the maintenance of disturbed social relationships. Kramer (1993) conducted a study with dyads of patients with Alzheimers' disease and their wives. These authors examined both positive relationship-focused strategies (empathic responding, support) and negative relationship-focused coping strategies (confronting, ignoring, blaming, avoidance, withdrawal). The results of this self-report study confirmed that the use of positive relationship focused coping strategies was associated with increased caregiver satisfaction and that negative relationship focused strategies was associated with depression in caregivers. According to Ell (1996) positive relationship-focused coping strategies are important and a lack of empathic responding results in harmful effects on patient recovery and impacts quality of life. Consequently, further research is required to explore empathic responding by informal caregivers from the patient's perspective.

*Quality of Life.* Quality of life has also been explored in relation to its effect on psychological distress. The negative effect of psychological distress on the quality of life of ovarian cancer patients has been reported. Kornblith et al. (1995) conducted a study (N=151) in order to determine the nature and extent of physical problems and psychological distress experienced by women with ovarian in order to assess their quality of life. Pain, and other physical symptoms, level of physical functioning, psychological state, and social functioning were evaluated using a detailed pain questionnaire, The Memorial Pain Assessment Card, The Memorial Symptom Assessment Scale, The Mental Health Inventory (MHI) the Functional Living Index- Cancer (FLIC) and the Karnofsky Performance Status. The investigators of this study reported that one-third of ovarian cancer patients experienced high levels of psychological distress and low quality

of life scores and that this was related to the severity of their physical symptoms as well as social support. They concluded that due to the prevalence of significant levels of psychological distress in ovarian cancer patients, more vigorous effort is required to identify, evaluate, and manage psychological distress, which would likely impact quality of life of ovarian cancer patients. Bodurka-Bervers et al. (2000) studied psychological distress (anxiety and depression), and quality of life in patients with epithelial ovarian cancer (N=244). These authors found results similar to those reported in the study by Kornblith et al. (1995) where high levels of psychological distress were correlated with increased physical symptoms and low quality of life.

#### *Demographics and Psychological Distress*

It is recognized that psychological distress is prevalent in ovarian cancer patients (Hipkins et al., 2005; McCorkle et al., 2003; Norton et al., 2004, Portenoy, Thaler, et al., 1994). However, psychological distress occurs with varying severity. Thus, in order to accurately assess its prevalence it is important to recognize patient characteristics and demographic factors such as age, education level, marital status, stage of cancer, ethnicity, religion, and income level that may be predictive or influential in the development and manifestation of psychological distress (Norton et al., 2004).

*Age.* The age of patients appears to be a mitigating factor when measuring psychological distress, with younger patients reporting more distress than older patients (Mathews et al., 2003; Turner et al., 2005). Norton et al., (2004) found that younger women did not cope as effectively as older women with a diagnosis of ovarian cancer and suggested that this was due perhaps to different expectations of the illness as well as changing roles and responsibility within the family. Merluzzi and Martinez-Sanchez

(1997) reported that increasing age is associated with greater adjustment, possibly due to older people being better adjusted psychologically in their close relationships than younger people. According to Manne and Schnoll (2001), older and more educated adults may have a greater sense of personal control over emotions and coping efficacy and therefore such emotions may hold less salience for older adults.

However, it is of interest to note that Zabora et al. (2001) reported that younger individuals (<30) and older individuals (<80) were more distressed than those between the ages of 30 and 60. According to Zabora et al. (2001) older individuals may experience multiple stressors in conjunction with a cancer diagnosis including the loss of a spouse and lower income levels.

*Level of Education.* The level of patient education may also influence psychological distress experienced by patients. Ben-Zur et al. (2001) reported that a high level of education among patients is linked with lower levels of distress and suggested that this was probably due to the fact that education is considered a personal resource that may enhance coping through ability to comprehend the situation as well as utilized information more effectively. Also, patients with a higher level of education are more likely to have a higher socioeconomic status. Low socioeconomic status has been associated with higher levels of psychological distress (O'Neil & Morrow, 2001).

*Marital Status.* The inverse relationship of marriage to distress has been reported in the literature. According to Zabora et al. (2001), married individuals have the lowest levels of distress, which confirms the significance of social support as patients cope with their illness. Dragaset and Lindstrom (2005) conducted a study aimed at examining demographic characteristics, social support, and coping in women with possible breast

cancer (N=117) and reported that women who were married coped more effectively with the possibility of having breast cancer. However, it should be noted that the quality of the marital relationship may also influence its relationship to distress (Long, 1990).

*Stage of Cancer.* The stage of cancer may also impact the level of psychological distress experienced by patients. According to Manne et al. (2000), early-stage patients may have higher expectations for their level of physical functioning, compared with late-stage patients. Late stage patients may lower their expectations as a way of preparing for deterioration and early-stage patients may be less prepared for a decline, resulting in more psychological distress. Alternatively, although early-stage cancer can be traumatic, the treatment is time-limited and the cure more certain (Manne et al., 2000). The treatment for late-stage cancer is less likely to be time-limited, and the potential for cure is less certain. This may be particularly significant in relation to the ovarian cancer population, as over 70% of patients are diagnosed at Stage III or Stage IV (Luce et al., 2003), leading to the very real possibility of dying (Howell et al., 2003).

*Cultural Background and Ethnicity.* The manifestation and expression of psychological distress may vary by cultural background or ethnicity. Zabora et al. (2001) conducted a study aimed at determining the prevalence of psychological distress in cancer patients and reported that African American individuals possessed a higher level of distress than their white counterparts. Although the reasons for this have not been delineated, this appears to be a consistent finding (O'Neil & Morrow, 2001).

Variations in expression due to cultural background may influence measurement of psychological distress. Chen, Chang, and Yeh (2000) reported that Chinese patients are less likely to report distress, due to culturally valued ideals of stoicism. Additionally,

immigrants, whose first language is not English, may experience higher levels of distress due to the difficulties in communication (O'Neil & Morrow, 2001; Turner et al., 2005).

*Religion.* Participation in religious practices has been associated with lower levels of psychological distress. Jarvis, Kirmayer, Weinfeld, and Lasry (2005) conducted a study (N=3,859) where they examined the relationship between religious practice and psychological distress and reported that overall attendance at religious services was associated with lower levels of psychological distress. Jarvis et al. (2005) proposed that this may be because involvement in religious practice augments social support and coping skills as well as providing a buffer against stressful life events. Merluzzi and Martinez-Sanchez (1997) reported that individuals who engaged in religious practices were better adjusted to their illnesses than those who did not engage in religious practices. According to Ferrel et al. (2003), (including religiosity) is a method of deriving meaning from the ovarian cancer experience and is associated with less distress.

*Income Level.* Socioeconomic status may also influence the development and degree of psychological distress. Throughout the literature, financial status has been associated with health status. According to Merluzzi and Martinez-Sanchez (1997), individuals with cancer who have higher incomes adjust to the disease better than individuals with lower incomes. Distress is inversely related to income (Zabora et al., 2001), and poverty has been identified as a major determinant in the evaluation and treatment of physical and psychological symptoms (O'Neil & Morrow, 2001).

### *Measuring Psychological Distress*

A variety of tools exist to measure psychological distress. These instruments have been empirically tested and are widely used within healthcare research. They were

developed for clinical use in the assessment of those patients who are at risk for and experience clinically significant levels of psychological distress which may impact health outcomes. The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) is commonly used in the assessment of psychological distress in the cancer population. Other tools that have been developed to measure psychological distress in a variety of populations include the Mental Health Inventory (MHI) (Veitt & Ware, 1983); The Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1971), The Psychological Distress Inventory (PDI) (Morasso, Constantini, Baracco, Borreani, & Cappelli, 1996), The Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis, 1983), The SCL-90-R (Derogatis, 1994), and The Brief Symptom Inventory (BSI) (Derogatis & Melisaratos, 1983), all of which will be discussed in the subsequent section.

*Mental Health Inventory (MHI).* The Mental Health Inventory (MHI) was developed in 1983 by Veit and Ware. The MHI is a 38-item measure of psychological distress and well-being. The MHI was developed for use in the general population and was tested in 4 samples (N=5089) of individuals between the ages of 13 and 69 years. The MHI is composed of a of a general underlying psychological distress vs. well-being factor, a higher order structure composed of 2 correlated factors (psychological distress and well-being) and 5 correlated lower order factors (Anxiety, Depression, Emotional Ties, General Positive Affect, and Loss of Behavioral Emotional Control). The authors of the MHI reported strong psychometric support as well as high internal consistency estimates (Veit & Ware, 1983). An analytic assessment of the MHI in measuring cancer patients' psychological distress and well-being was conducted by Manne and Schnoll (2001) in a sample of cancer patients (N=433). Structural equation modeling, and

confirmatory factor analyses (CFAs) were conducted prior to conducting an exploratory factor analysis (EFA). The investigators of this study reported that there were numerous differences in factor loadings and they concluded that the original MHI factor structure may require modification for use in patients with cancer. The MHI has been utilized to measure psychological distress in the ovarian cancer population by Kornblith et al. (1996). However, the MHI includes variables that measure well-being that are not consistent with the aims of this pilot study and is thus not appropriate.

*Profile of Mood States (POMS)*. The POMS was developed by McNair et al. in 1971 to identify and assess transient, fluctuating, affective states. The POMS is a self-rating instrument that is comprised of 65 adjective rating scales, and was developed and tested in a cohort of psychiatric outpatients (n=1,020) as well as normal college students (n=235). The POMS consists of six factorially-derived mood or affective states (McNair et al., 1971) including Tension-Anxiety; Depression-Dejection; Anger-Hostility; Vigor-Activity; Fatigue-Inertia; and Confusion-Bewilderment. The 65 adjective scales are rated based on intensity, and ask the respondent to rate adjectives such as "Tense" or "Annoyed" based on how he or she has been feeling over the past week. Adjectives are rated on a 5-point, Likert-type scale ranging from "Not at all" (0 points) to "Extremely" (4 points). Subsequent to totaling the scores from all six factors, a total mood disturbance score is obtained.

Internal consistency reliabilities as reported by the authors range from 0.84 to 0.95 among the six factors and test-retest reliability estimates range from 0.65 to 0.74 over periods ranging from three to 110 days in a sample of 100 patients. The POMS appears to be a reliable and valid instrument relevant to psychological assessment.

However, concerns regarding the inability to conduct meta-analytic investigations due to methodological variability in the use of the POMS have been cited (Edwards & Haythornthwaite, 2001). Consequently, Edwards and Haythornthwaite (2001) expressed concerns regarding whether the POMS can be verified as a psychometrically sound measure of mood. The length of the POMS has also been cited as a concern (Zabora et al., 2001). Curran, Andrykowski, and Studts (1995) also recognized that the length of the original POMS may limit its use with physically ill populations and evaluated a short version of the POMS (POMS-SF). Curran et al. (1995) reported internal consistency estimates for the POMS-SF were comparable to those of the original POMS. The POMS has been utilized within the cancer population. Dilorenzo, Bovbjerg, Montgomery, Valdimarsdottir, and Jacobsen (1999) utilized the 37-item version of the POMS in a sample of breast cancer patients (n=114) undergoing chemotherapy as well as healthy volunteers (n=55) and concluded that the 37 item POMS-SF (short form) could be of use if participant burden is of concern. However, it would be difficult to determine whether some of mood or affective states highlighted in the POMS (the Vigor-Activity; Fatigue-Inertia; and Confusion-Bewilderment) would be an accurate measure of psychological distress as they may mimic effects of the cancer and its treatment.

*Psychological Distress Inventory (PDI)*. The PDI is a 13-item, self rating survey that was developed by Morasso et al. (1996) to screen for psychological distress in cancer patients. The PDI evaluates the general emotional condition of the patient and the psychological disorders related to illness adjustment (Morasso et al., 2001). Each of the 13 items is rated on a 5-point Likert-type scale. Global scores range from 13 to 65 with higher scores reflecting greater distress. Morasso et al, (1996) tested the PDI in three

samples (N=434) of cancer patients and reported a Cronbach's alpha statistics at 0.88 for the study sample. The PDI also underwent concurrent validity testing with the State Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1970) and reported positive correlations with the STAI scales at  $>70$ . They concluded that the PDI is a reliable and valid tool for measuring psychological distress in cancer patients as well as in detecting psychiatric disorders through a screening procedure. The PDI has been utilized in the cancer population by the authors. However, this instrument assesses the general emotional state and does not specifically focus on psychological distress (comprised of anxiety and depression) as defined for the purposes of this study.

*Psychosocial Adjustment to Illness Scale (PAIS)*. The Psychosocial Adjustment to Illness Scale (PAIS) was developed by Morrow, Chiarello, and Derogatis (1978) in order to assess and measure the psychological as well as social adjustment of medically ill patients and their immediate relatives. The psychometric properties reported for this instrument indicate that it is a reliable and valid instrument in terms of measuring adjustment. However, as the PAIS is a measure of psychological adjustment, rather than distress (Zabora et al., 2001), it is inappropriate for this pilot study.

*SCL-90-R*. The SCL-90-R was developed by Derogatis (1994). This 90-item, self report instrument was formulated to quantify current psychological distress by measuring the existence and intensity of symptoms. The SCL-90 was tested based on the experiences of four populations including psychiatric outpatients, psychiatric inpatients, non-patient adults, and adolescent non-patients. This instrument is comprised of 90 statements that indicate possible psychological distress, including: "difficulty making decisions", and "feeling easily annoyed or irritated." Each item is rated on a 5-point,

Likert-type scale ranging from “not at all” (0 points) to “extremely” (4 points). The SCL-90 measures current psychological distress along nine symptom dimensions including: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. Three global indices of distress can be calculated: 1) Global Severity Index (GSI: current level of distress); 2) Positive Symptom Distress Index (PSDI-the intensity of distress); and 3) Positive Symptom Total (PST- the number of patient-reported symptoms. Internal consistency of this instrument was analyzed by the author who reported coefficient alpha ranges from 0.77 to 0.90. Test-retest reliability at one week was reported as between  $r=0.80$  to  $r=0.90$ . Although reliability and validity of this instrument have been reported as high, its length has been cited as an issue if burden is a concern (Zabora et al., 2001).

*Brief Symptom Inventory (BSI).* The BSI is a 53-item measure of psychological distress that is comprised of three global scales and nine subscales (Derogatis & Melisaratos, 1983). This instrument is a shortened version of the SCL-90-R and measures the same nine primary symptom dimensions (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism) and three global indices (Global Severity Index, Positive Symptom Distress Index, Positive Symptom Total). Like the SCL-90-R, respondents are asked to rate such as “feeling lonely even when you are with people” on a 5-point Likert-type scale ranging from “not at all” (0 points) to “extremely” (4 points).

The Cronbach alpha coefficients for the BSI ranged between 0.71 and 0.85, and test-retest reliability for the BSI at two weeks ranged from  $r=0.68$  to  $r=0.91$ , indicating that this is a valid and reliable instrument. Additionally, the BSI has been utilized within

the cancer population (Ben-Zur, Gilbar, & Lev, 2001; Zabora et al., 2001), and has been written at a 6<sup>th</sup> grade level, which may facilitate ease of comprehension. Norton et al. (2004) utilized the BSI in their study involving the prevalence of psychological distress in ovarian cancer patients (N=151). However, as the BSI includes somatic symptoms and does not focus on psychological distress as comprised of anxiety and depression alone, it does not fulfill the requirements of this pilot study

*Hospital Anxiety and Depression Scale (HADS).* The Hospital Anxiety and Depression Scale was developed by Zigmond and Snaith (1983) to assess anxiety and depression in medically ill patients. This 14-item scale assesses psychological distress (measured as anxiety and depression) via two seven-item subscales: HADS-ANXIETY (HADS-A) and HADS-DEPRESSION (HADS-D). Respondents are asked to rate statements aimed at assessing anxious and depressive symptoms over the past week on a 4-point Likert-type scale. The HADS has been widely used to assess psychological depression within the cancer population (Hipkins et al., 2005; Nordin et al., 2001; Petersen & Quinlivan, 2002; Smith et al., 2003). The HADS does not include somatic symptoms (which may be manifestations of the illness itself), and it thus has been cited as being important in the detection of psychological distress in patients with cancer and chronic illness (Hipkins et al., 2005; Nordin et al., 2001).

The HADS has been utilized with the ovarian cancer population. Hipkins et al. (2005) conducted a study involving Stage I to Stage IV ovarian cancer patients (N=63) undergoing chemotherapy in order to describe the levels of anxiety and depression (quantified by the HADS) in patients during the three month period following the end of chemotherapy treatment, as well as to identify factors that predict psychological

morbidity. They concluded that ovarian cancer patients experienced significant amount of psychological distress (manifested by anxiety and depression), and that social support and intrusive thoughts were the principal determinants of psychological morbidity in these patients. The HADS (Zigmond & Snaith, 1983) is a reliable, valid, and widely utilized instrument in the measurement of psychological distress in the cancer and non-cancer populations. The HADS measures psychological distress as defined for the purposes of this study and has been utilized successfully with ovarian cancer patients in the past. Thus, it is appropriate for use in this pilot study.

#### *Treatment and Management of Psychological Distress*

According to McCorkle et al. (2003) the appropriate treatment of psychological distress can improve the health outcomes of patients. Healthcare professionals who fail to address psychological symptoms can have negative consequences relevant to patient morbidity (Petersen & Quinlivan, 2002). The National Comprehensive Cancer Network (NCCN, 2005), stated that the appropriate treatment begins with the assessment and identification of patients experiencing psychological distress by utilizing assessment instruments. Once proper assessment and identification has been conducted, optimal management can ensue. As there are varying levels of psychological distress, a combination of interventions may be required (Petersen & Quinlivan, 2002).

Mild levels of psychological distress can be anticipated as an expected component of the cancer experience (Yarbro et al., 2004) and can be managed by the primary oncology team. Healthcare professionals must strive to incorporate distress management into the treatment regime and must ensure that the proper social and informational supports are available to patients and their families (NCCN, 2005). According to Turner

et al. (2005), current clinical practice guidelines for the psychosocial care of cancer patients advise clinicians to routinely assess the emotional and social issues of cancer patients, which may contribute to psychological distress. Severe or clinically significant levels of psychological distress should result in an immediate referral to a mental health professional, social worker, or pastoral worker (NCCN, 2005). Actual methods of intervention and treatment may include pharmacological therapy, and individual and group therapy that can be facilitated by breathing exercises, guided imagery and progressive muscle relaxation exercises among others (Petersen & Quinlivan, 2002).

### *Empathy*

Social support is an important aspect of health psychology and has important implications for patients adjusting to chronic illness or stressful life events (Long, 1990; Pistrang, Barker, & Rutter, 1997; Stymister & Friend, 2003). However, a fundamental weakness of social support research is that it essentially fails to recognize the 'social' aspects or actions and reactions that actually transpire between people that constitute support, including empathic behaviors (Pistrang et al., 1997). Empathy has been cited as an essential component for any helping relationship (Rogers, 1959; Hakansson & Montgomery, 2003) and empathic responding from caregivers has been positively associated with coping with illness (Coyne & Bolger, 1990) and lower levels of psychological distress (Ell, 1996).

In order to fully understand the impact of caregiver behaviors on patient coping, the concept of empathy must be explored. Empathy has been defined as "the identification with and understanding of another's situation, feelings, and motives" (Soukanov, 1996, p. 603), and an "objective, awareness of and insight into the feelings,

emotions, and behavior of another person and their meaning and significance” (Thomas, 1997, p. 629). Although it remains distinct, the concept of empathy has been associated with sympathy and pity (Soukanov, 1996). Empathy itself is a complex subject which, though often used, remains elusive (Long, 1990; White, 1997). In the literature, distinctions are made between basic empathy (that which naturally develops and is innate, emotional) and trained empathy (that which builds on basic empathy and develops through practice, which are driven by behavioral (communication skills) and moral (internal motivation to empathize) components (Long, 1990; Morse et al., 1992). Rogers (1980) described that empathy is the foundation for helping and effects therapeutic change. For the purposes of this study, empathic behaviors by informal caregivers are viewed as supportive behaviors that enhance communication competence by caregivers. This communication competence can serve to enhance the caregiver’s perceptual understanding and validation of patient illness experiences, which in turn, result in the patient feeling understood in their illness situation.

Davis (1980) proposed that perspective-taking, or “putting oneself in another person’s shoes” is considered a trait, capability, or skill that may be influential in generating perceptual understanding. Long (1990) described that perspective-taking is the cognitive component of empathic behavior. Lee, Brennan, et al. (2001) conducted a study with informal caregivers of older adults in order to determine the relationship between empathy, informal care-giving appraisal and outcomes (N=140). Based on the results of this study and caregiver outcomes these authors reported that caregivers with high levels of cognitive empathy (perspective-taking) appraised the situation as less threatening, were less depressed, and had higher life satisfaction. O’Brien and Delongis (1990)

described that the process of perspective-taking is a relationship-focused coping mechanism based on empathic responding that this is important to the management and resolution of interpersonal stressors. O'Brien and Delongis (1990) further argued that positive outcomes were more likely to occur if individuals engaged in empathic responding. The importance of perspective-taking has been empirically tested in relation to caregiver perceptions of patient symptom experiences (Kramer, 1993; Lobchuk and Vorauer, 2003). Lobchuk and Vorauer (2003) examined underlying perspective taking processes that drive empathic behaviors and hypothesized that perspective-taking enhances observer understanding and perceptual accuracy of caregivers in assessing patient symptoms. The results of Lobchuk and Vorauer's study (N=98) suggested that family caregivers were likely to overestimate patient symptoms, particularly psychological symptoms if they did not engage in empathic responding. As family members have been increasingly acting as primary caregivers in the homecare setting who provide either 'proxy' or 'complementary' information, proper assessment of both physical and psychological symptoms from a patient-oriented viewpoint is important in relation to patient care.

According to (Mcilveen, 1992), empathic behavior has a significant effect on the meaning of illness. In a study conducted by (Reid-Ponte, 1992), the empathic behavior of nurses was found to be correlated with patient satisfaction and level of psychological distress. Norton et al. (2005) found that social support and empathic behavior from family members as perceived by ovarian cancer patients were positively correlated with self-esteem and perceived control, which impacted the psychological distress experienced by these patients.

### *Summary*

A review of the literature pertinent to the study of physical symptom experiences, empathic behaviors of caregivers, and psychological distress in ovarian cancer patients has been presented. Individuals with ovarian cancer experience physical symptoms associated with the management and treatment of their disease, as well as from the disease itself. As ovarian cancer is not usually diagnosed until later stages (which results in a poor prognosis), it is often associated with high levels of psychological distress. The variance of psychological distress in this population has resulted in the realization that psychological status must be influenced by factors other than physical symptom experience. Social support from informal caregivers has been recognized as important in terms of coping with the cancer experience. A lack of empathic responding (e.g. perspective taking) by informal caregivers has been associated with feelings of neglect and abandonment for those suffering with the disease, as well as increased physical symptoms and psychological distress. However, more research is needed in order to empirically substantiate the association between empathic informal caregiver behavior, physical symptom experience, and psychological distress in ovarian cancer patients.

## CHAPTER THREE

### Conceptual Framework

This study was guided by the stress, appraisal, and coping theory developed by Lazarus and Folkman (1984). It appeared from the literature review that Lazarus and Folkman's theory captures relationships among the concepts of patient physical symptom experiences, empathic behaviors of caregivers, and patient psychological distress. The investigator adapted this framework to conceptualize the influence of social support or empathic behaviors, and relationship-focused coping between the patient and informal caregivers to understand their influence on physical symptoms experience and psychological distress in ovarian cancer patients.

According to Lazarus and Folkman (1984), when a stressful event or stressor (such as physical illness) occurs, the patient undergoes the process of primary appraisal, which results in the assessment of a situation (as in this study, the occurrence of physical symptoms) as threatening or benign. This appraisal is influenced by a variety of factors, including personal and environmental resources that can ultimately impact an individual's ability to cope with a situation effectively (as in this study, the occurrence of psychological distress). Personal and environmental resources or factors can include age, education, marital status, stage of cancer, type of cancer, past and current treatment, ethnicity, religion, occupational status, and current employment. In this study, the investigator also identified the empathic behavior of the caregiver as personal resource of the ovarian cancer patient. Depending on the patient's level of social support or caregiver empathic behaviors, the patient's physical symptom experiences and psychological distress can be negatively or positively impacted.

A stressor, according to Lazarus and Folkman, is defined as “a specific external or internal demand that is appraised as taxing or exceeding the resources of the person” (p. 21). According to Lazarus and Folkman (1984) there are two main methods that individuals engage in to cope with stressors that include positive, problem-focused coping or negative, emotion-focused coping. O’Brien and Delongis (1990) described that coping effectively with interpersonal stressors can be more effectively managed by relationship-focused strategies, or empathic behavior. According to O’Brien and Delongis (1990), empathy is a form of coping. Empathic behavior involves an effort to engage in perspective-taking in order to vicariously experience the involved other’s feelings and concerns and to create one’s own affective and cognitive associations relevant to that experience. Empathic behavior or relationship focused coping also involves efforts aimed at interpreting the psychological states underlying the other’s verbal and nonverbal communication, and efforts to respond sensitively to another person out of a state of concern or to express caring or understanding in an accepting, nonjudgmental and emotionally validating manner (p.783).

Physical disability or impairment is widely recognized as a contributor to psychological distress, and aversive or unsupportive reactions and interactions with family and friends can be an extremely important source of stress for individuals with cancer (Manne et al., 1997). Investigators involving ovarian cancer patients appeared to recognize the significance of social support as an indicator of psychological distress. Hipkins et al. (2005) concluded that lack of social support is a significant predictor of psychological distress in ovarian cancer patients and that future studies should include social support when assessing for psychological symptoms. Norton et al. (2004) also

recognized that there are non-medical stressors that are likely contributors to the development of psychological distress, and highlighted the need to explore the relationship between informal caregiver behavior and the psychological distress of ovarian cancer patients.

Based on the above and drawing on Lazarus and Folkman's (1984) adapted model (Figure 1) this framework postulated that the perceived empathic behavior from informal caregivers might result in a benign appraisal (appraisal as non-threatening). This appraisal is then related to a decreased incidence of psychological distress and less bothersome physical symptoms due to a strengthening of the personal resources of the ovarian cancer patient. As guided by Lazarus and Folkman's model, it is also plausible that when the patient perceives the informal caregiver does not engage in empathic behaviors, the patient's personal resources decrease and the physical symptom experience is appraised as more threatening by the patient. This, in turn, can result in increased psychological distress experienced by the ovarian cancer patient.

The aim of this pilot study was to glean a preliminary understanding of the associations among empathic behaviors of informal caregivers, patient physical symptom experiences, and patient psychological distress in the ovarian cancer population. Psychological distress (emotional outcome) is influenced by empathic behaviors. This research proposed that the empathic behavior of the informal caregivers as perceived by the ovarian cancer patient will influence symptom experience. This, in turn will impact psychological distress. The results of this study may be significant in providing foundational evidence that supports the future development of a behavioral intervention

involving patients and informal caregivers that can serve to impact both the physical symptom experience and the psychological distress of ovarian cancer patients.

## CHAPTER FOUR

### Methodology

#### *Introduction*

This chapter describes the research design and methodology by providing information relevant to the research design, sample, setting, as well as data collection methods and procedure employed by the investigator. The rationale for utilizing the selected data collection instruments will be included, and discussion relevant to ethical implications will follow.

#### *Design*

This pilot study employed a descriptive correlational research design. According to Polit and Beck (2004), the rationale for conducting descriptive correlational research is to describe the relationships among variables rather than to infer cause-and-effect relationships. The dependent variable relevant to this study included psychological distress (i.e. anxiety and depression) reported by the patient. The independent variables consisted of perceived empathic informal caregiver behaviors and physical symptom experiences as reported by the patient. In a supplemental analysis, some patient socio-demographic characteristics (age, educational status, annual family income, length of time caregiver has been caring for patient, patient perception of caregiver knowledge of physical symptoms and emotions, and degree of contact) were examined in an exploratory manner as to their relationship with physical symptom experience and psychological distress.

The main purpose of this study was to determine whether perceived empathic behaviors of informal caregivers are associated with psychological distress and physical

symptom experience of women with ovarian cancer. The investigator was also interested in obtaining prevalence information on patient physical symptom experiences, empathic behaviors of caregivers, and patient psychological distress in the target population, as well as determining the concurrent validity of two tools designed to capture the empathic behaviors of caregivers.

### *Setting*

Ovarian cancer patients were recruited from an outpatient clinic setting at CancerCare Manitoba, Winnipeg, Manitoba, Canada. This clinic was chosen because it is one of two major referral centers for cancer patients in Manitoba with responsibility for cancer prevention, detection, care, research and education for the people of Manitoba (CCMB, 2005), and it receives referrals for all ovarian cancer patients in Winnipeg (Dr. R. Lotocki, personal communication, November 4, 2005).

Recruitment for this pilot study was based out of a primary clinic for Gynecologic Oncology (Clinic III) and a psychosocial oncology support group at Cancer Care Manitoba. This clinic was chosen because it has the highest volume of ovarian cancer referrals in Winnipeg, Manitoba therefore deeming this clinic site as appropriate to obtain an adequate sample within a six month period of data collection for this pilot study.

### *Sample*

The target population for this pilot study included patients who had been diagnosed with stage I – stage IV ovarian cancer, regardless of whether they were undergoing treatment at the time of the interview. A convenience sample of adult women was recruited based on the eligibility criteria described below, at the MacCharles site of

CancerCare Manitoba. A convenience sample was chosen due to the feasibility of accruing an adequate sample within a six month span at CancerCare Manitoba, MacCharles site, which reported a total of 72 ovarian cancer patients in 2004. Of the 72 patients, 42 patients died the same year (J. Kostyra, personal communication, December 9, 2005). Current patient statistics for this clinic site were not available to assist the investigator in identifying the population of ovarian cancer patients in recurrent and active disease stages who would be eligible to approach as potential participants in the current study (Dr. R. Lotocki, personal communication, January 3, 2006). The investigator's thesis committee members agreed that a sample of 12 to 20 ovarian cancer patients would be appropriate for this pilot study.

#### *Inclusion Criteria*

In order to determine eligibility for participation in this study, the following inclusion criteria were established. The patient must be: (a) medically diagnosed with Stage I, II, III, or IV ovarian cancer; (b) cognitively capable of responding to survey questions per the physician or nurse assessment; (c) over the age of 18 years; (d) able to read, speak, write, and understand English; and (e) able to identify an informal primary caregiver who assists them in coping with their illness. For the purposes of the pilot study, an informal caregiver was defined as a voluntary caregiver who assists another person to fulfill his or her needs (Lee, Brennan, et al., 2001). Informal care-giving often involves friendships or family ties (Lee, Brennan, et al., 2001).

The thesis committee members determined that the investigators' pilot project will provide important preliminary data on relationships among the study variables. With the assistance of Dr. Lotocki, who is an experienced gynecologic oncologist at

CancerCare Manitoba, the committee members agreed that a sample size ranging between 12 and 20 patients over six months would suffice for preliminary analysis, and to address feasibility issues in conducting telephone survey interviews with ovarian cancer patients. All patients who met the eligibility criteria and consented to participate in this study were included. A total of thirteen participants were obtained during the six month data collection period from March 2006 until August 2006.

### *Method*

#### *Procedure*

Data collection commenced subsequent to obtaining ethical approval by the *Education and Nursing Ethics Review Board* at the University of Manitoba, and site approval to access subjects and medical records by the *Resource Impact Committee* at CancerCare, Manitoba.

The recruitment protocol involved a clinic site and a support group site at the MacCharles unit, CancerCare Manitoba, Winnipeg, Manitoba. In the clinic setting and on scheduled clinic days for ovarian cancer patients, the oncologists identified eligible, cognitively capable patients and indicated patient eligibility on patient appointment cards. The clinic clerk then provided patients with a letter of invitation to the study (Appendix A). The clinic clerk attempted to retrieve all letters of invitation that were provided to eligible patients on which they would indicate whether or not they were in agreement to speak to the investigator further about the study. Attached to this letter were two copies of the informed consent form (Appendix B). One copy was provided for the patient's personal use and the second copy was to be signed and returned to the investigator in a self-addressed, stamped envelope.

Once a week, the investigator collected the returned letters of invitation from the clinic clerk. If the patient agreed to speak with the investigator, she then telephoned the patient to explain the study and the patient's involvement as a possible study participant. If the patient agreed, the investigator asked the patient to sign and mail the consent form in the self-addressed, stamped envelope, and then proceeded to schedule a date and time for the telephone interview that would be convenient for the patient.

In light of the slow accrual of patients from the clinic setting (zero patients were recruited after one month) an additional recruitment site was determined appropriate. Additional recruitment of patients was sought from ovarian cancer support groups at Cancer Manitoba, Psychosocial Oncology Department. The recruitment protocol entailed that ovarian cancer patients were provided with letters of invitation by the social worker hosting the support group meetings. The social worker provided the investigator with the letters of invitation indicating (by checking a 'yes' or 'no') whether or not patients were willing to speak to the investigator. The investigator telephoned the patients who agreed and explained the study and the patient's involvement as a possible study participant. If the patient agreed, the investigator asked the patient to sign and mail the consent form, and scheduled a date and time for the telephone interview that would be convenient for the patient.

Prior to obtaining the patient's responses to the survey questions, the investigator reviewed the study information with the patient, answered any questions she may have had, and secured written consent in accordance with the policies and procedures highlighted in the CancerCare Manitoba, *Health Sciences Centre Research Review Board*. During the interview, every reasonable effort was made to ensure confidentiality

and privacy. The investigator conducted the telephone interviews in a sound proof room with the door closed. The investigator ensured that the patient felt comfortable disclosing information by telephone. The investigator advised the patient that, if there was any discomfort due to lack of privacy in the home setting at the time of the interview, the interview could be rescheduled at the patient's convenience. During the telephone interviews, six surveys were administered by the investigator. The patients required approximately 60 minutes to complete the interview.

### *Instruments*

The first instrument was a patient demographic questionnaire aimed at obtaining a description of the sociodemographic, illness and treatment-related, and caregiving relationship characteristics of the current study's sample. The second instrument administered was the HADS (Zigmond & Snaith, 1983). This instrument provided comprehensive description of levels of anxiety, depression, and overall psychological distress experienced by patients. The third instrument administered was O'Brien and Delongis's (1990) Empathic Responding Scale which provided information on the patients' perception of empathic caregiver behaviors. The fourth instrument was the MSAS (Portenoy, Thaler, et al., 1994). The MSAS provided data on the patients' overall symptom experience. The fourth and fifth instruments encompassed patient self-assessment and patient perception of informal caregiver empathic behaviors that were measured by Long's (1990) Perspective-Taking Tool.

*Patient Demographic Questionnaire (Appendix C).* The investigator developed the appended socio-demographic questionnaire that included items about the patient's age, marital status, language, ethnicity, religion, occupation, and care-giving relationship.

In instances where the patient could not reliably recall her medical information, the investigator obtained permission to access the patient's medical records. All information obtained from the patient's medical records was kept confidential and handled in accordance with the Personal Health Information Act (PHIA) guidelines.

*Hospital Anxiety and Depression Scale (HADS) (Appendix D).* The HADS (Zigmond & Snaith, 1983) was utilized to quantify the dependent variable, psychological distress and includes emotional symptoms of anxiety and depression. The HADS assesses anxiety and depression using a self-report format and consists of 14 items, divided into two subscales, HADS-ANXIETY (HADS-A) and HADS-DEPRESSION (HADS-D). Each subscale consists of seven items, which are rated on a 4-point Likert scale scored from zero to three and target patient feelings over the past week. Scoring of the subscales ranges from zero (no distress) to 21 (maximum distress), with a score of seven or less being "normal", eight to ten as "doubtful, or borderline", and 11 or greater as "clinically significant" (Zigmond & Snaith, 1983). The HADS has been widely used since its development within the cancer and non-cancer population. The internal consistency has been reported to be as high as 0.93 for anxiety and 0.90 for depression (Petersen & Quinlivan, 2002), indicating a high level of reliability.

*Empathic Responding Scale (Appendix E).* The Empathic Responding Scale was designed by O'Brien and DeLongis (1990) to assess empathic responding of undergraduate psychology students to evaluate the impact of social relationships on coping with stressful situations. This scale was found to have a Cronbach's alpha coefficient of 0.93 relevant to empathic responding when assessed in a sample of undergraduate students (N=270). Kramer (1993) used this scale in a sample of 72 dyads

of wives who were caring for husbands with Alzheimer's disease. Kramer found evidence to support the idea that coping mechanisms employed by caregivers was related to different types of stressors they are subject to and the resources available to them. No reliability or validity estimates for the Empathic Responding Scale were provided by Kramer (1993).

The investigator adapted the Empathic Responding Scale with permission from one of the tool's authors (Dr. A. Delongis, personal communication, December 1, 2005) to measure the patient's perception of her informal caregiver's empathic behavior. The investigator explored the concurrent validity of this tool, or the degree to which the Empathic Responding Scale scores were correlated with Long's Dyadic Perspective-Taking Tool in capturing patient perceived empathic responding of informal caregiver in correlation with Long's (1990) Dyadic Perspective-Taking tool. The results from this psychometric analysis will provide valuable information for the investigator's future doctoral work on the measurement of relationship coping or empathic caregiver behaviors with a valid and reliable tool that reduces burden for patients to complete.

*Memorial Symptom Assessment Scale (MSAS) (Appendix F).* The MSAS was developed by Portenoy, Thaler, et al. (1994) to quantify the symptom experiences of a mixed cancer, palliative patient population. The MSAS is a self-rating instrument that measures the multidimensional symptoms associated with the cancer experience. The MSAS is comprised of a 32 items that capture the multidimensional experiences of physical and psychological symptoms including presence, severity, and frequency as captured on a four or five-item Likert-type Scale (Portenoy, Thaler, et al., 1994). Frequency, severity, and distress (three of the dimensions) are incorporated into 24 of the

evaluated items, and severity and distress (the two other dimensions) comprise the eight remaining items on the scale. Patients were required to indicate the presence of a symptom, and then rate the severity, frequency, and distress for the identified symptom.

Portenoy, Thaler, et al. (1994) assessed the reliability of the MSAS involving a random sample (N=246) consisting of prostate, colon, ovarian, and breast cancers and determined high internal consistency for the psychological symptom subscale (0.83 Cronbach's alpha coefficient), as well as the physical-high frequency subscale (0.88 Cronbach's alpha coefficient). These authors found a moderate internal consistency at 0.58 Cronbach's alpha for the physical-low frequency subscale.

Portenoy, Kornblith, et al. (1994) used the MSAS to obtain detailed information on the prevalence, characteristics of pain, and associated symptoms in patients (N=151) with all stages of ovarian cancer. In response to the pain item on the MSAS, 60% of ovarian cancer patients reported having pain during the previous week. However, detailed questions about the experience of pain as being persistent or frequent resulted in a prevalence of only 42%. According to Portenoy, Kornblith, et al. (1994), although a small proportion of patients reported inconsistently, the use of descriptive wording (frequency, severity, distress) is a valid method for identifying subgroups of patients who experience more severe physical symptoms and require further assessment. Portenoy, Kornblith, et al. (1994) also reported prevalence rates for psychological distress in this population as exceeding 50% and noted that the MSAS data demonstrates the diversity of symptoms experienced by ovarian cancer patients.

Both physical subscales (PHYS-H & PHYS-L) of the MSAS were utilized in this pilot study to measure physical symptom experiences of ovarian cancer patients. The

rationale for use of the MSAS physical symptom subscale is its development and use within the ovarian cancer population. Although Portenoy, Kornblith, et al. (1994) did not report reliability or validity of the MSAS in their study with ovarian cancer patients, it was suggested that the descriptive characteristics of the MSAS provided a valid method for identifying patients who experience more severe pain. Furthermore, Portenoy, Thaler, et al. (1994) have established that the MSAS is a reliable symptom measurement instrument in a population that included ovarian cancer patients. There is ongoing testing that supports the psychometric properties of the MSAS. According to Chang et al. (2000) the Memorial Symptom Assessment Scale (MSAS) has been validated and can be described as a comprehensive and multifaceted symptom assessment tool that measures the severity, frequency and distress associated with 32 highly prevalent symptoms and is of use with the cancer population.

*Perspective-Taking Tool (PTP) and (PTCG) (Appendices G and H).* The fourth and fifth questionnaires were developed by Long (1990) and were adapted to assess the patient's view of her own empathic behavior towards her informal caregiver (PTP) (Appendix G), and the patient's perception of her informal caregiver's empathic behavior (PTCG) (Appendix H). Each scale is comprised of 20 items that are evaluated based on a 5 item, Likert type scale, ranging from 0 to 4 with 0 being "Does not describe me (my caregiver) very well" and 4 being "Does describe me (my caregiver) very well." The Other Dyadic Perspective-Taking Tool (ODPT) was originally developed to measure the individual's perception of dyadic perspective-taking of his or her partner (Long, 1990). For the purposes of this study, this tool was modified to measure the patient self-report of perspective taking behaviors within the context of the patient-informal caregiver

relationship, in addition to measuring the patient's perception of the informal caregiver's perspective-taking behaviors. Reliability and validity for this tool has been established with alpha coefficient values reported from a sample of married couples (N=342) at .93 for husbands and .95 for wives on the ODPT (Long & Andrews, 1990). Lobchuk (2001) has employed this tool with advanced cancer patients and their informal caregivers. Lobchuk (2001) reported an internal consistency reliability estimate for the ODPT subscale at 0.93, which closely corresponds with findings reported by Long & Andrews (1990).

### *Ethical Implications*

As this study included human subjects, it was reviewed by three committees prior to initiation of data collection. The thesis committee initially approved this thesis during the proposal stage in January 2006. Ethical approval was subsequently sought and approved by the *Education and Nursing Ethics Board* at the University of Manitoba in February 2006. Research approval and site access were provided by the Resource Impact Committee, CancerCare Manitoba in February 2006. Data collection commenced in March 2006 and concluded at the end of August 2006.

### *Patient Risk.*

It was recognized that the subject matter of the interview could be emotionally disruptive for some patients. Therefore, and as indicated on the informed consent form (Appendix B), the investigator allowed extra time on the telephone with those individuals who exhibited high distress (as indicated by a high score on the HADS and/or in accordance with the investigator's assessment of the patient's behaviors during the telephone interview). Additionally, the investigator stopped the interview, unless the

patient wished to continue, to further assess the patient's feelings. The investigator also inquired as to whether the patient's primary oncology team was aware of her feelings and whether the patient was undergoing psychological intervention. The investigator also provided the patient with contact information at the CancerCare Manitoba Department of Psychosocial Oncology. However, if the patient requested, the investigator contacted the Department of Psychosocial Oncology on the patient's behalf in order to facilitate a referral.

#### *Informed Consent and Confidentiality*

Prior to signing consent, all participants were provided with verbal and written information regarding the study and were assured that their responses would remain anonymous and confidential. The patients were also informed that they had the freedom to withdraw from the study at any time and that their care would not be affected in any way. The investigator also explained that their participation in this study was conditional upon completion of compulsory informed consent. The consent was provided in writing and completed by the patient who signed and dated the informed consent (Appendix B). The consent letter contained contact information of the investigator, thesis supervisor, and Human Ethics Secretariat, should the patient have had further questions about the study.

To protect the confidentiality of the patient and to safeguard the information collected, all surveys were numerically coded and stored in locked filing cabinets at the investigator's home. The signed, informed consents were separately stored in a locked filing cabinet at the investigator's home. All of this data was stored in a secure place

where only the investigator had access to any and all information. All data will be destroyed after 7 to 10 years of concluding this study via a confidential paper shredder.

### *Data Analysis*

The analyses of data involved a variety of statistical tests deemed to be appropriate for each research question as determined in consultation with a statistician located at the Manitoba Nursing Research Institute (M. Cheang, personal communication, September 28, 2006). The computer package SPSS 14.0 for Windows was used to analyze the data. The Cronbach's alpha coefficient, a widely used indicator of reliability according to Polit and Beck (2004), was reported on all instruments prior to addressing the research questions.

To describe the overall sample, sociodemographic characteristics descriptive statistics were employed that included frequency counts, means and standard deviations on sociodemographic and illness and treatment related variables. Research question #1 stated, "What is the prevalence of empathic informal caregiver behavior, physical symptom experience, and psychological distress in Stage I - Stage IV ovarian cancer patients?" Frequency counts, means, and standard deviations were conducted to describe the prevalence of patient physical symptom experiences, empathic behaviors of the informal caregiver as perceived by the patient, and patient psychological distress.

Research question #2 stated, "Are there associations among empathic informal caregiver behaviors, patient's physical symptom experiences, and patient's psychological distress?" Non-parametric Spearman's rank correlational analyses of ordinal data were employed in order to determine associations between physical symptom experience, caregiver empathic behaviors, and psychological distress. The investigator's intent was to

regress psychological distress on physical symptom experience and empathic relationship coping variables. However regression analysis was precluded due to the small number of patient participants ( $n = 13$ ) accrued in the current study (M. Cheang, personal communication, September 28, 2006).

Research question #3 stated, "What is the concurrent validity of the Empathic Responding Scale (O'Brien & Delongis, 1990) compared with the Perspective-Taking Tool (Long, 1990)?" Statistical analyses involved testing the concurrent validity, or the degree to which scores on an instrument are correlated with some external criterion (Polit & Beck, 2003). For this research question, the Empathic Responding Scale (O'Brien & Delongis, 1990) was correlated with Long's Perspective-Taking Tool (Long, 1990). For all tests, the significance level was set at  $p \leq 0.05$ .

#### *Summary*

This chapter outlined the methods that were used to carry out a descriptive correlational study aimed at exploring relationships among physical symptom experience, empathic coping, and psychological distress of ovarian cancer patients. The study was guided by the Stress, Appraisal and Coping Theory developed by Lazarus and Folkman (1984). The theoretical framework guided the investigator's exploration of relationships among physical symptom distress, empathic behavior of informal caregivers, and patient psychological distress in ovarian cancer patients. A physical symptom distress scale, anxiety and distress scale, two empathic coping scales, and a demographic data form were used to collect data over the telephone from patient participants. Results of reliability and validity assessments for the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), Empathic Responding Scale (O'Brien & Delongis,

1990), The Memorial Symptom Assessment Scale (MSAS) (Portenoy, Thaler, et al., 1994), and Perspective-Taking Tool (Long, 1990) were discussed indicating that psychometric criteria were met. The subject criteria and data collection protocol were discussed, including ethical protocol. The procedure for assuring subject confidentiality was also discussed. The data analysis plan was described that answered the questions: 1) What is the prevalence of empathic informal caregiver behaviors, physical symptom experience, and psychological distress in Stage I - Stage IV ovarian cancer patients?; 2) Are there associations among empathic informal caregiver behaviors, patient's physical symptom experiences, and patient's psychological distress?; and 3) What is the concurrent validity of the Empathic Responding Scale (O'Brien & Delongis, 1990) compared with the Perspective-Taking Tool (Long, 1990)?

## CHAPTER FIVE

### Results

The purpose of this study was to investigate the linkage between empathic informal caregiver behaviors, physical symptom experiences, and psychological distress experienced by patients with Stage I- Stage IV ovarian cancer. This chapter describes the characteristics of the patient sample and reports on the reliability of the instruments employed with this study's patient sample. Statistical analyses of the research questions are presented in conjunction with a report of major findings.

The specific research questions were:

1. What is the prevalence of empathic informal caregiver behavior, physical symptom experience, and psychological distress in Stage I - Stage IV ovarian cancer patients?
2. Are there associations among empathic informal caregiver behaviors, patient's physical symptom experiences, and patient's psychological distress?
3. What is the concurrent validity of the Empathic Responding Scale (O'Brien & Delongis, 1990) compared with the Perspective-Taking Tool (Long, 1990)?

Participants were recruited over a six month period between March 2006 and August 2006 from CancerCare Manitoba (Health Sciences Centre). Data collected from each of the patient participants included a data demographic questionnaire, the HADS (Zigmond & Snaith, 1983), The Empathic Responding Scale (Delongis, 1990), the MSAS (Portenoy, Thaler, et al., 1994), and the Perspective-Taking Tools (Long, 1990).

#### *Demographic Data*

This study yielded a non-probability convenience sample of 13 participants (n=13) recruited from CancerCare Manitoba (Health Sciences Centre, MacCharles Unit).

These were participants who indicated on the written invitation that they agreed to speak to the investigator about the study. All eligible participants who agreed to speak to the investigator, were contacted by the investigator and had consented to participate in the study. Five eligible patients received a written invitation in the clinic from the clinic clerk and 13 eligible patients received a written invitation from a social worker in the Psychosocial Oncology Support Group to speak to the investigator about their interest in speaking to the investigator about the study. In total, 15 patients responded to the invitation to speak to the investigator. Of the 15 patients who returned written invitations, 13.3 % (n = 2) patients refused and 86.7% (n = 13) agreed to speak to the investigator about the study. All 13 patients who spoke to the investigator about the study agreed to be study participants. These patients were recruited from the support groups held at CancerCare Manitoba. The investigator did not recruit any patients from the clinic setting. Fifteen letters of invitation were provided to the clinic clerk for distribution to eligible patients. Only five letters were provided to eligible patients (two patients indicated that that they did not wish to speak to the investigator about the study, and three patients did not return the letter of invitation to the clinic clerk). The limited distribution of letters of invitation in the clinic setting occurred due to a small number of patients attending the clinic setting, and many of the same patients were being seen in this clinic setting on a repeated basis over the six month time of data collection. Furthermore, due to the challenges of working in a busy clinic setting, the unit clerk was prevented from offering the letter of invitation to all eligible patients who had attended that clinic. Table 5.1 represents the demographic information provided by the patient participants of this study.

Table 5.1 Demographic Data

Characteristic	Total Sample (n=13)	Percent
Age Range (years)		
43 ≤ 59	7	53.8%
60 ≥ 73	6	46.2%
Mean 58.7		
Type of Cancer		
Epithelial	12	92.3%
Sex Cord Stromal	0	0.0%
Germ Cell	0	0.0%
Unknown	1	7.7%
Stage of Cancer		
Stage I	1	7.7%
Stage II	1	7.7%
Stage III	10	76.9%
Stage IV	1	7.7%
Unknown	0	0.00%
Time Since Diagnosis (Months)		
0-18	3	23.1%
19-36	6	46.2%
>36	4	30.7%
Current Treatment		
None	8	61.5%
Chemotherapy	5	38.5%
Radiotherapy	0	0.00%
Surgery	0	0.00%
Other	0	0.00%
Past Treatment		
None	1	7.7%
Chemotherapy	11	86.1%
Radiotherapy	0	0.0%
Surgery	10	76.9%

Other *Adds up to more than 100% due to multiple treatment modalities.	0	0.0%
Language		
English	13	100.00%
French	0	0.0%
Other	0	0.0%
Cultural/Ethnic		
Canadian	5	38.5%
European	6	46.2%
Middle Eastern	2	15.3%
Religiosity		
No Preference	1	7.7%
Jewish	1	7.7%
Lutheran	1	7.7%
Catholic	4	30.7%
United Church	3	23.1%
Buddhist	3	23.1%
Level of Education		
Less than high school	1	7.7%
High School Graduate	5	38.4%
Partial College	2	15.4%
College or University Graduate	3	23.1%
Graduate/Professional Training	2	15.4%
Marital Status		
Married/Common-Law	11	84.6%
Never Married/Separated	2	15.4%
Occupational Status		
Employed	5	38.4%
Medical Leave /Unemployed/ Retired	8	61.6%

Occupation		
Laborer	1	7.7%
Homemaker	1	7.7%
Professional	3	23.1%
Management	1	7.7%
Other	7	53.8%
Annual Family Income		
\$31,000-\$60,000	5	38.4%
\$61,000-\$90,000	5	38.4%
Refused	3	23.1%
Receiving Nursing Service		
No	13	100%
Yes	0	0.0%
Patient perception of the:		
Length of Time Caregiver Caring for Participant (Months)		
0 to 36	4	30.8%
More than 36	9	69.2%
Extent to Which Caregiver assists in Coping with Medical Condition and Physical Symptoms		
Rarely/ Sometimes	4	30.8%
Frequently/ Always	9	69.2%
Extent to which Caregiver assists in coping with emotions		
Rarely/ Sometimes	6	46.2%
Frequently/ Always	7	53.8%
Do Participant and Caregiver talk openly about thoughts and feelings regarding symptoms?		

Never/ Rarely/Sometimes	5	38.4%
Frequently/ Always	8	61.6%
Do Participant and Caregiver talk openly about thoughts and feelings regarding emotions?		
Never/Rarely/Sometimes	9	61.2%
Frequently/ Always	4	39.8%
How well does caregiver know how you think and feel about symptoms?		
Not at All/ Not Very Well	2	15.4%
Some/ Adequate	5	38.4%
Very Well	6	46.2%
How well does caregiver know how you think and feel about emotions?		
Not at All/ Not Very Well	3	23.2%
Some/ Adequate	5	38.4%
Very Well	5	38.4%
Degree of Contact		
Daily	11	84.6%
More than weekly	2	15.4%

According to the data set, the majority of participants were under the age of fifty-nine (53.8%) and identified themselves as being married or living with a common-law partner (84.6%). All participants identified English as being the language spoken at home and a majority of participants identified themselves as being of European descent (46.2%), followed closely by those identifying themselves as Canadian (38.5%). Religiosity was widely varied with a small majority of participants identifying themselves as being of the Catholic faith (30.7%) and equal numbers identifying themselves as being of United Church (23.1%) and Buddhist (23.1%) faiths. The level of education in this group ranged from less than completion of high school to graduate or professional training, however a slight majority of patients identified their highest educational training as graduation from high school (38.4%). A majority of the participants identified themselves as being unemployed or on medical leave (61.6%) and an equal number of participants reported their annual family income level as being below \$60,000 (38.4%) and above \$61,000 (38.4%). All patient participants reported having recurrent epithelial ovarian cancer with a majority (76.9%) being diagnosed with stage III disease. Treatment consisted primarily of surgery (76.9%) and chemotherapy (86.1%) in the past, with 38.5% currently being treated with chemotherapy.

Most participants reported being cared for by their caregiver for more than 36 months (69.2%) and as having daily contact with their caregiver (84.6%). The majority of participants reported that their caregivers always or frequently helped them to cope with the physical (69.2%) as well as emotional (53.8%) aspects of their medical condition. Although (61.6%) of participants were able to speak openly with their caregiver about the physical aspects of their disease, only (39.8%) were able to speak

openly with their caregivers regarding emotional aspects of their disease. Patient reports of whether they felt that their caregivers understood their thoughts and feelings regarding physical and emotional aspects of their illness were widely varied, with 15.4% of participants reporting that their caregiver did not understand physical aspects very well/or not at all and 23.2% reporting their caregivers not understanding emotional aspects very well/not at all.

### *Reliability of Instruments*

According to Polit and Beck (2004), reliability coefficients are important indicators of an instruments' quality. Instruments that are unreliable do not provide appropriate or sufficient means to test hypotheses. Thus, knowledge regarding an empirical instruments' reliability is of utmost importance when conducting and analyzing research. Cronbach's alpha coefficient is the most frequently utilized measure of reliability and internal consistency and instruments reporting coefficients above .70 are considered sufficiently reliable and those above .80 are considered highly reliable (Polit & Beck, 2004). Table 5.2 represents the computed Cronbach's alpha coefficients for the empirical instruments used in this study. As evidenced by Table 5.2, most instruments are highly reliable, with the exception of the HADS, which reported being sufficiently reliable. The HADS reliability coefficient is slightly lower in this study in comparison to other studies (Hipkins et al., 2005; Petersen & Quinlivan, 2002). This could be due, partially, to the small sample size. According to Polit and Beck (2004), the reliability of an instrument is a property not of the instrument, but rather of the instrument when administered to a certain sample under certain conditions.

Table 5.2. Reliability of instruments

<b>Instrument</b>	<b>Cronbach's Alpha</b>
MSAS	0.904
Empathic Responding Scale	0.934
Perspective-Taking Tool (PTP)	0.813
Perspective-Taking Tool (PTCG)	0.827
HADS	0.774

*Analysis of the Research Questions*

*Research Question #1: What is the prevalence of physical symptom experience, empathic informal caregiver behaviors and psychological distress in stage I to stage IV ovarian cancer patients?*

*Prevalence of physical symptom experiences.* The prevalence of physical symptom experiences was captured by patient responses on the Memorial Symptom Assessment Scale (Portenoy, Thaler, et al., 1994). Patients were asked if they had experienced each symptom over the past week. Patients were required to give a 'yes' or 'no' answer which was followed by the investigator checking 'did not have' or continuing with assessment of frequency, severity and distress (See Table 5.3). The mean number of reported patient symptoms was 6.53 (SD  $\pm$  5.92), with a range of one to 22 symptoms. More than 50% of patients reported that they experienced lack of energy and sweats, and 46.2% reported tingling or numbness in the hands or feet over the past week. Less than 10 percent of patients reported problems with urination, vomiting, problems with sexual interest/activity, itching, difficulty swallowing and hair loss.

In addition to patient reports on the 'presence' of physical symptoms over the past week, Table 5.4 represents the MSAS percentage ratings as follows: for severity, the percentages are based on patients who reported it was moderate (score of 2) to very severe (score of 4); for frequency, the percentages are based on patients who reported in was frequent (score of 3) to almost constantly (score of 4); and, for distress, the percentages are based on patients who reported it was quite a bit (score of 3) to very much (score of 4). Certain items were not evaluated for frequency including: mouth

Table 5.3 MSAS Prevalence of Physical Symptoms in Ovarian Cancer Patients

Symptoms	'Yes' Response ( N=13)
Pain	5 (38.5%)
Lack of Energy	8 (61.5%)
Cough	3 (23.1%)
Dry Mouth	5 (38.5%)
Nausea	3 (23.1%)
Feeling Drowsy	5 (38.5%)
Numbness/Tingling in Hands/Feet	6 (46.2%)
Feeling Bloating	4 (30.8%)
Problems with Urination	1 (7.7%)
Vomiting	1 (7.7%)
Shortness of Breath	5 (38.5%)
Diarrhea	2 (15.4%)
Problems with Sexual Interest or Activity	0
Itching	1 (7.7%)
Sweats	7 (53.8%)
Dizziness	1 (7.7%)
Difficulty Swallowing	1 (7.7%)
Lack of Appetite	3 (23.1%)
Mouth Sores	2 (15.4%)
Change in the way food tastes	4 (30.8%)
Weight Loss	2 (15.4%)

Constipation	5 (38.5%)
Swelling of Arms or Legs	2 (15.4%)
Hair Loss	1 (7.7%)
"I don't look like myself"	4 (30.8%)
Changes in Skin	5 (38.5%)

sores, changes in the way that food tastes, weight loss, constipation, swelling of arms or legs, hair loss, "I don't look like myself", and changes in skin. These items were only evaluated for severity and distress in accordance with Portenoy, Thaler, et al.'s (1994) scoring guidelines.

*Frequency.* As displayed in Table 5.4, when patients reported the 'presence' of symptoms, the symptom with the highest frequency (i.e., a rating of 3 or 4) of occurrence was lack of energy. Patients reported sweats, and tingling or numbness in the hands or feet as the second and third most frequently occurring symptoms.

*Severity.* According to Table 5.4, dry mouth, feeling drowsy, feeling bloated, problems with urination, vomiting, shortness of breath, diarrhea, sweats, swelling in arms or legs, and hair loss were the most severe symptoms (i.e., a rating of 2, 3, or 4) reported by patients, followed by numbness or tingling in the hands or feet, changes in skin, lack of energy, changes in the way that food tastes and sweats.

*Distress.* According to Table 5.4, numbness or tingling in the hands and feet, dry mouth, drowsiness, shortness of breath, weight loss, changes in the way food tastes, constipation, and changes in skin were reported by patients as causing the most distress (i.e., a rating of 3 or 4). Little or no distress was reported from the following symptoms: cough problems with urination, difficulty swallowing, lack of appetite, weight loss, hair loss, feelings such as 'I don't look like myself' and changes in skin.

Supplemental analyses of the underlying symptom dimensions of frequency, severity, and distress as captured on the MSAS sub-scales revealed that, although 75% of patients experienced 'frequent' and 'severe' lack of energy, only 25% were quite distressed by it. Likewise, of those who experienced sweats, although 42.8 % of patients

Table 5.4 MSAS Characteristics of Physical Symptoms in Ovarian Cancer Patients

Symptom	Frequency (Freq-Con) Scores 3-4	Severity (Mod-Very Severe) Scores 2-4	Distress (Quite a Bit- Very Much) Scores 3-4
Pain	3/5 (60.0%)	3/5 (60.0%)	3/5 (60.0%)
Lack of Energy	6/8 (75.0%)	6/8 (75.0%)	2/8 (25.0%)
Cough	0/3 (0.0%)	0/3 (0.0%)	0/3 (0.0%)
Dry Mouth	5/5 (100%)	5/5 (100%)	1/5 (20.0%)
Nausea	2/3 (66.7%)	2/3 (66.7%)	2/3 (66.7%)
Feeling Drowsy	4/5 (80.0%)	5/5 (100%)	2/5 (40.0%)
Numbness/Tingling in Hands/Feet	3/6 (50.0%)	5/6 (83.3%)	1/6 (16.0%)
Feeling Bloating	3/4 (75.0%)	4/4 (100%)	3/4 (75.0%)
Problems with Urination	0/1 (0.0%)	1/1 (100%)	0/1 (0.0%)
Vomiting	0/1 (0.0%)	1/1 (100%)	1/1 (100%)
Shortness of Breath	3/5 (75.0%)	5/5 (100%)	1/5 (20.0%)
Diarrhea	1/2 (50.0%)	2/2 (100%)	1/2 (50.0%)
Problems with Sexual Interest or Activity	0/0 (0.0%)	0/0 (0.0%)	0/0 (0.0%)
Itching	1/1 (100%)	1/1 (100%)	1/1 (100%)
Sweats	3/7 (42.8%)	5/7 (71.4%)	2/7 (28.5%)
Dizziness	0/1 (0.0%)	1/1 (100%)	1/1 (100%)
Difficulty Swallowing	0/1 (0.0%)	0/1 (0.0%)	0/1 (0.0%)

Lack of Appetite	1/3 (33.3%)	1/3 (33.3%)	0/3 (0.0%)
Mouth Sores	n/a	1/2 (50.0%)	0/2 (0.0%)
Change in the way food tastes	n/a	3/4 (75.0%)	1/4 (25.0%)
Weight Loss	n/a	1/2 (50.0%)	0/4 (0.0%)
Constipation	n/a	4/5 (80.0%)	2/5 (40.0%)
Swelling of Arms or Legs	n/a	2/2 (100%)	2/2 (100%)
Hair Loss	n/a	1/1 (100%)	0/1 (0.0%)
"I don't look like myself"	n/a	2/4 (50.0%)	0/4 (0.0%)
Changes in Skin	n/a	4/5 (80.0%)	0/5 (0.0%)

Note: The following abbreviations mean: Freq-Con (Frequently to Constantly); Mod- V Severe (Moderate to Very Severe)

reported experiencing them frequently and 71.4% reported it as being significantly severe, again only 28.5% of participants reported being distressed by this symptom. Furthermore, although greater than 50% of patients reported the numbness or tingling in the hands and feet, dry mouth, drowsiness, shortness of breath, weight loss, changes in the way food tastes, constipation, and changes in skin as being severe (i.e., ratings of 2, 3, or 4), less than 40% of the same patients reported being highly distressed (i.e., ratings of 3 or 4) by these symptoms.

Other symptoms, although some were quite severe, caused little or no distress in this patient population, including cough, problems with urination, difficulty swallowing, lack of appetite, weight loss, hair loss, feelings such as 'I don't look like myself' and changes in skin. Interestingly, as evidenced by the data set, the presence of or frequency with which patients reported experiencing a symptom over the past week did not appear to be related to severity or distress caused by the symptom. In other words, just because a patient reported experiencing a particular symptom frequently over the past week, it did not mean that this symptom caused the patient distress. Conversely, just because a patient did not report that she experienced a symptom frequently or severely over the past week, it did not mean that the symptom was not distressful. Thus, there does not appear to be a direct linkage between the frequency, severity or distress of symptoms.

Descriptive analysis also included a report of patient mean responses to underlying dimensions of 26 symptoms, including severity, frequency, and distress, as well as total individual symptom experience scores, and total MSAS score (see Table 5.5). The theoretical range of means was between zero and four. The total MSAS score was the average of the symptom scores across 26 physical symptoms. Total symptom

Table 5.5 MSAS Mean Scores

Symptom	Patient N	Range of scores	Mean Patient Score	Standard Deviation
<b>Pain</b>	5	0.67-3.00		
Frequency			2.40	1.34
Severity			1.60	.548
Distress			1.80	1.64
Total			1.93	1.64
<b>Lack of Energy</b>	8	0.67-3.67		
Frequency			2.75	.886
Severity			2.00	.756
Distress			1.88	1.35
Total			2.20	.974
<b>Cough</b>	3	1.00-1.33		
Frequency			2.00	0.00
Severity			1.00	0.00
Distress			.33	.577
Total			1.11	.192
<b>Dry Mouth</b>	5	1.67-3.67		
Frequency			3.40	.548
Severity			2.60	.894
Distress			1.80	1.48
Total			2.60	.795
<b>Nausea</b>	3	1.00- 3.33		
Frequency			2.33	1.15
Severity			2.33	1.52
Distress			2.33	1.15
Total			2.33	1.20
<b>Feeling Drowsy</b>	5	2.00- 3.33		
Frequency			2.80	.447
Severity			2.80	.837
Distress			2.60	.894
Total			2.73	.596
<b>Numbness/Tingling in Hands/Feet</b>	6	1.33-3.67		
Frequency			3.00	1.09
Severity			2.33	1.03
Distress			1.33	1.03
Total			2.22	.807
<b>Feeling Bloated</b>	4	2.67- 3.33		
Frequency			3.00	.816
Severity			2.25	.500
Distress			3.25	.957
Total			2.83	.333

<b>Problems with Urination</b>	1	2.33- 2.33		
Frequency			3.00	.
Severity			2.00	.
Distress			2.00	.
Total			2.33	.
<b>Vomiting</b>	1	2.33- 2.33		
Frequency			1.00	.
Severity			2.00	.
Distress			4.00	.
Total			2.33	.
<b>Shortness of Breath</b>	5	1.67- 4.00		
Frequency			3.00	1.00
Severity			2.40	.894
Distress			2.00	1.22
Total			2.46	.960
<b>Diarrhea</b>	2	2.00- 3.67		
Frequency			2.00	1.41
Severity			3.50	.707
Distress			3.00	1.41
Total			2.83	1.17
<b>Problems with Sexual Interest or Activity</b>		0; 0		
Frequency			0.00	.
Severity			0.00	.
Distress			0.00	.
Total			0.00	.
<b>Itching</b>	1	2.67- 2.67		
Frequency			3.00	.
Severity			2.00	.
Distress			3.00	.
Total			2.66	.
<b>Sweats</b>	7	1.33- 2.33		
Frequency			2.29	7.56
Severity			1.86	.690
Distress			1.71	1.49
Total			1.95	.405
<b>Dizziness</b>	1	2.33- 2.33		
Frequency			2.00	.
Severity			2.00	.
Distress			3.00	.
Total			2.33	.
<b>Difficulty Swallowing</b>	1	1.33- 1.33		
Frequency			2.00	.

Severity			1.00	.
Distress			1.00	.
Total			1.33	.
<b>Lack of Appetite</b>	3	1.33- 2.67		
Frequency			2.67	1.15
Severity			2.00	1.73
Distress			1.00	1.00
Total			1.88	.693
<b>Mouth Sores</b>	2	1.00- 2.00		
Severity			1.50	.707
Distress			1.50	.707
Total			1.50	.707
<b>Change in the way food tastes</b>	4	1.00- 3.00		
Severity			2.25	1.25
Distress			2.25	1.25
Total			2.25	.957
<b>Weight Loss</b>	2	0.50- 1.00		
Severity			1.50	.707
Distress			0.00	0.00
Total			0.75	.353
<b>Constipation</b>	5	0.50- 4.00		
Severity			2.40	1.14
Distress			2.00	1.58
Total			2.20	1.30
<b>Swelling of Arms or Legs</b>	2	2.00- 3.00		
Severity			2.50	.707
Distress			2.50	.707
Total			2.50	.707
<b>Hair Loss</b>	1	2.00- 2.00		
Severity			4.00	.
Distress			0.00	.
Total			2.00	.
<b>"I don't look like myself"</b>	4	0.50- 2.00		
Severity			1.50	.577
Distress			1.25	.957
Total			1.37	.629
<b>Changes in Skin</b>	5	0.50- 2.50		
Severity			2.20	.837
Distress			1.40	.894
Total			1.80	.836
<b>TOTAL MSAS score</b>				

	13	0.50- 50.17	1.93	.576
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Note: Higher values on the symptom items indicate higher frequency with which the symptom occurred, greater severity of the symptom, and the more distress that the symptom produced. n/a (not applicable). Unlisted values are due to limited responses. Values entered as. indicate too few cases for the analysis.

Total symptom score is the average of the scores on the severity, frequency, and distress scales, or if appropriate, on the severity and distress scales only.

Total MSAS score is the average of the symptom scores for 26 symptoms.

scores consisted of the average of the scores on the severity, frequency, and distress sub-scales, or if appropriate, on the severity and distress sub-scales only. If a symptom dimension was not experienced, each dimension was scored zero, and the score for that dimension was zero. The values for severity and frequency were scales one to four, where one was 'slight' on the severity scale, and 'rarely' on the frequency scale, and four was 'very severe' on the severity scale and 'almost constantly' on the frequency scale. The average total MSAS score on the global scale was 1.93 (SD  $\pm$  .576). The lowest total MSAS score on individual symptom scales was zero on problems with sexual interest/activity.

This is consistent with Fitch, Gray, and Fransson's (2003) study involving ovarian cancer patients (n=146) where sexuality did not emerge as a problem by participants in that study. The symptoms with the highest total symptom mean scores were feeling bloated (m= 2.83) and diarrhea (m = 2.83). The symptoms that had the highest mean frequency scores as reported by patients, in rank order of mean scores, were dry mouth (m = 3.40) followed by numbness/tingling in hands/feet, feeling bloated, problems with urination, shortness of breath, and itching, all of which had a score of (m = 3.00). The most severe symptoms as reported by patients in rank order of mean scores included hair loss (m = 4.00), diarrhea (m = 3.50), and feeling drowsy (m = 2.80). The most distressing symptoms in rank order included vomiting (m = 4.00), feeling bloated (m = 3.25), diarrhea (m = 3.50), itching (m = 3.00), and dizziness (m = 3.00).

*Prevalence of Empathic Informal Caregiver Behaviors.* The prevalence of informal caregiver empathic behavior was analyzed through use of the Perspective – Taking Scale (Long, 1990) (see Table 5.6) and the Empathic Responding Scale (O'Brien

& DeLongis, 1990) (see Table 5.7). As an additional measure of empathic behaviors in the caregiving relationship, the investigator also captured the patient's self-report of empathic coping behaviors.

Across the 20 scaled items on the Perspective-Taking Tools, the total mean scores on the PTP and PTCG scales were similar at 2.74 (SD  $\pm$  .589) and 2.46 (SD  $\pm$  .596) respectively. The apparent concordance in mean scores indicates that the patient and the caregiver were engaging in similar levels of empathic behaviors, at least as perceived by the patient. In addition, of the theoretical range of scores between 0 and 4 on the Perspective-Taking Tools where higher ratings indicated increased empathic behaviors, the patient appeared to perceive that both oneself and the caregiver engaged in moderate levels of empathic behaviors in the caregiving relationship. The Spearman's rank correlation coefficient (*rho*) between the total scores on the two Perspective-Taking Tools by Long (1990) was 0.735 ( $p = 0.004$ ). This result indicates that, at the global level, the patient's perception of one's own and the caregiver's empathic behaviors were in concordance with one another and suggest a certain level of reciprocity in their caregiving relationship. According to Long (1990), highly correlated results may reveal one partner's sensitivity to the needs, interests, and desires of the spouse and is therefore positively related to marital adjustment. The rationale behind measuring both the patient self-perception of empathic coping behaviors and patient perception of caregiver empathic coping behaviors is that different scores may reveal existing conflict within the patient-caregiver relationship in accordance with the patient's viewpoint of the relationship.

Table 5.6. Patient perception of self and caregiver empathic relationship behaviors  
(Long, 1990)

<b>PT Items</b>	<b>Patient self-report Frequency</b>	<b>Min to Max Score</b>	<b>Mean (SD)</b>	<b>Perception of Caregiver Frequency</b>	<b>Min to Max Score</b>	<b>Mean (SD)</b>
<p>1. When involved in an argument with (me) my caregiver, I am (my caregiver is) the type of person who will consider and take into account my caregiver's (my) point of view and compare that with my own (caregiver view).</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe me well (1)</p> <p>-Describes me adequately (2)</p> <p>-Describes me well (3)</p> <p>-Describes me very well (4)</p>	<p>1 (7.7%)</p> <p>1 (7.7%)</p> <p>2 (15.4%)</p> <p>4 (30.8%)</p> <p>5 (38.5%)</p>	<b>0-4</b>	<b>2.85 (SD ± 1.28)</b>	<p>2 (15.4%)</p> <p>1 (7.7%)</p> <p>1 (7.7%)</p> <p>9 (69.2%)</p> <p>0</p>	<b>0-3</b>	<b>2.31 (SD ± 1.18)</b>
<p>2. I am not (my caregiver is not) good at understanding my (patient's) caregiver's problems.</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe me well (1)</p> <p>-Describes me adequately (2)</p> <p>-Describes me well (3)</p> <p>-Describes me very well (4)</p>	<p>(46.2%)</p> <p>1 (7.7%)</p> <p>5 (38.5%)</p> <p>1 (7.7%)</p> <p>0</p>	<b>0-3</b>	<b>1.08 (SD ± 1.15)</b>	<p>5 (38.5%)</p> <p>2 (15.4%)</p> <p>3 (23.1%)</p> <p>2 (15.4%)</p> <p>1 (7.7%)</p>	<b>0-4</b>	<b>1.38 (SD ± 1.39)</b>

<p>3. I (my caregiver) not only listen to what my caregiver (I am) is saying but really understand where my caregiver is coming from.</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe me well (1)</p> <p>-Describes me adequately (2)</p> <p>-Describes me well (3)</p> <p>-Describes me very well (4)</p>	<p>0</p> <p>1 (7.7%)</p> <p>4 (30.8%)</p> <p>4 (30.8%)</p> <p>4 (30.8%)</p>	<p><b>1-4</b></p> <p><b>2.85</b> <b>(SD ± 0.98)</b></p>	<p>0</p> <p>0</p> <p>4 (30.8%)</p> <p>4 (30.8%)</p> <p>5 (38.5%)</p>	<p><b>2-4</b></p> <p><b>3.08</b> <b>(SD ± 0.86)</b></p>
<p>4. I (my caregiver) do not seem to know how my caregiver (I) feels.</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe me well (1)</p> <p>-Describes me adequately (2)</p> <p>-Describes me well (3)</p> <p>-Describes me very well (4)</p>	<p>5 (38.5%)</p> <p>1 (7.7%)</p> <p>4 (30.8%)</p> <p>2 (15.4%)</p> <p>1 (7.7%)</p>	<p><b>0-4</b></p> <p><b>1.46</b> <b>(SD ± 1.39)</b></p>	<p>2 (15.4%)</p> <p>5 (38.5%)</p> <p>2 (15.4%)</p> <p>3 (23.1%)</p> <p>1 (7.7%)</p>	<p><b>0-4</b></p> <p><b>1.69</b> <b>(SD ± 1.25)</b></p>
<p>5. I (my caregiver) am able to accurately compare my caregiver's (my) point of view with my own.</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe me well (1)</p> <p>-Describes me</p>	<p>1 (7.7%)</p> <p>1 (7.7%)</p>	<p><b>0-4</b></p> <p><b>2.77</b> <b>(SD ± 1.30)</b></p>	<p>1 (7.7%)</p> <p>3 (23.1%)</p>	<p><b>0-4</b></p> <p><b>2.46</b> <b>(SD ± 1.33)</b></p>

adequately (2)	3 (23.1%)			1 (7.7%)		
-Describes me well (3)	3 (23.1%)			5 (38.5%)		
-Describes me very well (4)	5 (38.5%)			3 (23.1%)		
6. I (my caregiver) evaluate my caregiver's (my) motivation for doing something before I (my caregiver) make judgments about a situation.		<b>0-4</b>	<b>2.92</b> <b>(SD ± 1.18)</b>		<b>0-4</b>	<b>2.62</b> <b>(SD ± 1.12)</b>
-Does not describe me very well (0)						
-Does not describe me well (1)	1 (7.7%)			1 (7.7%)		
-Describes me adequately (2)	0			1 (7.7%)		
-Describes me well (3)	3 (23.1%)			2 (15.4%)		
-Describes me very well (4)	4 (30.8%)			7 (53.8%)		
	5 (38.5%)			2 (15.4%)		
7. I (my caregiver) easily become impatient with my caregiver (me).		<b>0-4</b>	<b>2.54</b> <b>(SD ± 1.45)</b>		<b>0-4</b>	<b>1.62</b> <b>(SD ± 1.55)</b>
-Does not describe me very well (0)	2 (15.4%)			5 (38.5%)		
-Does not describe me well (1)	1 (7.7%)			1 (7.7%)		
-Describes me adequately (2)	2 (15.4%)			3 (23.1%)		
-Describes me well (3)	4 (30.8%)			2 (15.4%)		
-Describes me very well (4)	4 (30.8%)			2 (15.4%)		
8. I (my caregiver) am not able to put myself into my caregiver's (my) shoes.		<b>0-3</b>	<b>1.23</b> <b>(SD ± 1.16)</b>		<b>0-4</b>	<b>2.23</b> <b>(SD ± 1.64)</b>
-Does not describe						

me very well (0)	5 (38.5%)			3 (23.1%)		
-Does not describe me well (1)	2 (15.4%)			1 (7.7%)		
-Describes me adequately (2)	4 (30.8%)			4 (30.8%)		
-Describes me well (3)	2 (15.4%)			0		
-Describes me very well (4)	0			5 (38.5%)		
9. I (my caregiver) nearly always know what my caregiver (I) means.		<b>0-4</b>	<b>2.62</b> (SD $\pm$ 1.60)		<b>2-4</b>	<b>2.77</b> (SD $\pm$ 0.83)
-Does not describe me very well (0)	2 (15.4%)			0		
-Does not describe me well (1)	2 (15.4%)			0		
-Describes me adequately (2)	1 (7.7%)			6 (46.2%)		
-Describes me well (3)	2 (15.4%)			4 (30.8%)		
-Describes me very well (4)	6 (46.2%)			3 (23.1%)		
10. I (my caregiver) do not sense or realize what my caregiver (I am) is saying.		<b>0-3</b>	<b>1.23</b> (SD $\pm$ 1.01)		<b>0-4</b>	<b>1.46</b> (SD $\pm$ 1.33)
-Does not describe me very well (0)	3 (23.1%)			4 (30.8%)		
-Does not describe me well (1)	6 (46.2%)			3 (23.1%)		
-Describes me adequately (2)	2 (15.4%)			3 (23.1%)		
-Describes me well (3)	2 (15.4%)			2 (15.4%)		
-Describes me very well (4)	0			1 (7.7%)		
11. I (my caregiver) realize what my caregiver (I) means even		<b>1-4</b>	<b>3.00</b> (SD $\pm$ 1.08)		<b>2-4</b>	<b>3.00</b> (SD $\pm$ 0.81)

when he/she has difficulty saying it.						
-Does not describe me very well (0)	0			0		
-Does not describe me well (1)	2 (15.4%)			0		
-Describes me adequately (2)	1 (7.7%)			4 (30.8%)		
-Describes me well (3)	5 (38.5%)			5 (38.5%)		
-Describes me very well (4)	5 (38.5%)			4 (30.8%)		
12. I (my caregiver) do not usually understand the whole meaning of what my caregiver (I) is saying to me.		<b>0-4</b>	<b>1.85</b> <b>(SD ± 1.35)</b>		<b>0-4</b>	<b>2.00</b> <b>(SD ± 1.15)</b>
-Does not describe me very well (0)	3 (23.1%)			1 (7.7%)		
-Does not describe me well (1)	2 (15.4%)			4 (30.8%)		
-Describes me adequately (2)	3 (23.1%)			3 (23.1%)		
-Describes me well (3)	4 (30.8%)			4 (30.8%)		
-Describes me very well (4)	1 (7.7%)			1 (7.7%)		
13. I (my caregiver) appreciate how the things my caregiver (I) experiences feel to him/her.		<b>1-4</b>	<b>3.15</b> <b>(SD ± 1.07)</b>		<b>0-4</b>	<b>3.15</b> <b>(SD ± 1.14)</b>
-Does not describe me very well (0)	0			1 (7.7%)		
-Does not describe me well (1)	1 (7.7%)			0		
-Describes me adequately (2)	3 (23.1%)			1 (7.7%)		
-Describes me well (3)	2 (15.4%)			5 (38.5%)		
-Describes me very well (4)	7 (53.8%)			6 (46.2%)		

<p>14. Before criticizing my caregiver (me), I (my caregiver) try to imagine how he/she feels.</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe me well (1)</p> <p>-Describes me adequately (2)</p> <p>-Describes me well (3)</p> <p>-Describes me very well (4)</p>	<p>0</p> <p>1 (7.7%)</p> <p>3 (23.1%)</p> <p>3 (23.1%)</p> <p>6 (46.2%)</p>	<p>1-4</p>	<p><b>3.08</b> (SD <math>\pm</math> 1.04)</p>	<p>0</p> <p>2 (15.4%)</p> <p>4 (30.8%)</p> <p>3 (23.1%)</p> <p>4 (30.8%)</p>	<p>1-4</p>	<p><b>2.69</b> (SD <math>\pm</math> 1.09)</p>
<p>15. If I (my caregiver) think I am right about something I don't waste much time listening to my (patient's) caregiver's arguments.</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe me well (1)</p> <p>-Describes me adequately (2)</p> <p>-Describes me well (3)</p> <p>-Describes me very well (4)</p>	<p>4 (30.8%)</p> <p>0</p> <p>2 (15.4%)</p> <p>3 (23.1%)</p> <p>4 (30.8%)</p>	<p>0-4</p>	<p><b>2.23</b> (SD <math>\pm</math> 1.70)</p>	<p>1 (7.7%)</p> <p>2 (15.4%)</p> <p>2 (15.4%)</p> <p>4 (30.8%)</p> <p>4 (30.8%)</p>	<p>0-4</p>	<p><b>2.62</b> (SD <math>\pm</math> 1.32)</p>
<p>16. I (my caregiver) try to understand my caregiver (me) better by imagining how things look from his/her perspective.</p> <p>-Does not describe me very well (0)</p> <p>-Does not describe</p>	<p>1 (7.7%)</p>	<p>0-4</p>	<p><b>2.77</b> (SD <math>\pm</math> 1.30)</p>	<p>1 (7.7%)</p>	<p>0-4</p>	<p><b>2.85</b> (SD <math>\pm</math> 1.28)</p>

me well (1)	1 (7.7%)			1 (7.7%)		
-Describes me adequately (2)	3 (23.1%)			2 (15.4%)		
-Describes me well (3)	3 (23.1%)			4 (30.8%)		
-Describes me very well (4)	5 (38.5%)			5 (38.5%)		
17. I (my caregiver) believe that there are two sides to every story and I (my caregiver) try to look at both sides.		<b>2-4</b>	<b>3.23</b> <b>(SD ± 0.93)</b>		<b>0-3</b>	<b>1.23</b> <b>(SD ± 1.09)</b>
-Does not describe me very well (0)	0			2 (15.4%)		
-Does not describe me well (1)	0			0		
-Describes me adequately (2)	4 (30.8%)			4 (30.8%)		
-Describes me well (3)	2 (15.4%)			7 (53.8%)		
-Describes me very well (4)	7 (53.8%)			0		
18. I (my caregiver) sometimes find it difficult to see things from my (patient's) caregiver's perspective.		<b>0-4</b>	<b>2.46</b> <b>(SD ± 1.39)</b>		<b>0-4</b>	<b>1.92</b> <b>(SD ± 1.38)</b>
-Does not describe me very well (0)	2 (15.4%)			3 (23.1%)		
-Does not describe me well (1)	1 (7.7%)			1 (7.7%)		
-Describes me adequately (2)	2 (15.4%)			5 (38.5%)		
-Describes me well (3)	5 (38.5%)			2 (15.4%)		
-Describes me very well (4)	3 (23.1%)			2 (15.4%)		
19. I (my caregiver) try to look at my caregiver's (patient's) perspective		<b>2-4</b>	<b>3.38</b> <b>(SD ± 0.79)</b>		<b>0-4</b>	<b>2.92</b> <b>(SD ± 1.25)</b>

before making a decision.						
- Does not describe me very well (0)	0			1 (7.7%)		
-Does not describe me well (1)	0			1 (7.7%)		
-Describes me adequately (2)	2 (15.4%)			1 (7.7%)		
-Describes me well (3)	4 (30.8%)			5 (38.5%)		
-Describes me very well (4)	7 (53.8%)			5 (38.5%)		
20. When I am (my caregiver is) upset with my caregiver (me), I (my caregiver) try to put myself in his/her (my) shoes for awhile.		<b>0-4</b>	<b>1.92</b> <b>(SD ± 1.60)</b>		<b>0-4</b>	<b>1.85</b> <b>(SD ± 1.28)</b>
-Does not describe me very well (0)	4 (30.8%)			3 (23.1%)		
-Does not describe me well (1)	1 (7.7%)			1 (7.7%)		
-Describes me adequately (2)	3 (23.1%)			5 (38.5%)		
-Describes me well (3)	2 (15.4%)			3 (23.1%)		
-Describes me very well (4)	3 (23.1%)			1 (7.7%)		
			<b>Total Score:</b> <b>2.74</b> <b>(SD ± .589)</b>			<b>Total Score</b> <b>2.46</b> <b>(SD ± .596)</b>

Note: The Total score for the scales was derived by the average of mean responses across 20 items multiplied by 13 respondents.

Table 5.7. Empathic Responding Scale (O'Brien &amp; DeLongis, 1990)

PT Items	Patient self-report Frequency	Min to Max Score	Mean (SD)
<p>1. My caregiver tries to understand my concerns.</p> <p>-Does not describe my caregiver very well (0)</p> <p>-Does not describe my caregiver well (1)</p> <p>-Describes my caregiver adequately (2)</p> <p>-Describes my caregiver well (3)</p> <p>-Describes my caregiver very well (4)</p>	<p>0</p> <p>1 (7.7%)</p> <p>0</p> <p>4 (30.8%)</p> <p>8 (61.5%)</p>	<p>1- 4</p>	<p><b>3.46</b> <b>(.877)</b></p>
<p>2. My caregiver tries to understand how I feel.</p> <p>-Does not describe my caregiver very well (0)</p> <p>-Does not describe my caregiver well (1)</p> <p>-Describes my caregiver adequately (2)</p> <p>-Describes my caregiver well</p>	<p>0</p> <p>1 (7.7%)</p> <p>1 (7.7%)</p>	<p>1- 4</p>	<p><b>3.31</b> <b>(.947)</b></p>

(3) -Describes my caregiver very well (4)	4 (30.8%) 7 (53.8%)		
3. My caregiver tries to experience what I am feeling		0- 4	<b>1.69 (1.43)</b>
-Does not describe my caregiver very well (0)	4 (30.8%)		
-Does not describe my caregiver well (1)	1 (7.7%)		
-Describes my caregiver adequately (2)	5 (38.5%)		
-Describes my caregiver well (3)	1 (7.7%)		
-Describes my caregiver very well (4)	2 (15.4%)		
4. My caregiver tries to help me by listening to me.		0- 4	<b>3.23 (1.01)</b>
-Does not describe my caregiver very well (0)	0		
-Does not describe my caregiver well (1)	1 (7.7%)		
-Describes my caregiver adequately (2)	2 (15.4%)		
-Describes my caregiver well (3)	3 (23.1%)		

-Describes my caregiver very well (4)	7 (53.8%)		
5. My caregiver tries to help me by doing something for me.		2- 4	<b>3.46 (1.09)</b>
-Does not describe my caregiver very well (0)	0		
-Does not describe my caregiver well (1)	0		
-Describes my caregiver adequately (2)	2 (15.4%)		
-Describes my caregiver well (3)	3 (23.1%)		
-Describes my caregiver very well (4)	8 (61.5%)		
6. My caregiver tries to figure out what would make me feel better.		1- 4	<b>2.77 (1.09)</b>
-Does not describe my caregiver very well (0)	0		
-Does not describe my caregiver well (1)	2 (15.4%)		
-Describes my caregiver adequately (2)	3 (23.1%)		

-Describes my caregiver well (3)	4 (30.8%)		
-Describes my caregiver very well (4)	4 (30.8%)		
7. My caregiver tries to comfort me by telling me about their positive feelings for me.		0- 4	<b>3.00 (1.35)</b>
-Does not describe my caregiver very well (0)	1 (7.7%)		
-Does not describe my caregiver well (1)	1 (7.7%)		
-Describes my caregiver adequately (2)	2 (15.4%)		
-Describes my caregiver well (3)	2 (15.4%)		
-Describes my caregiver very well (4)	7 (53.8%)		
8. My caregiver tries to imagine him/herself in my shoes.		0- 4	<b>1.69 (1.37)</b>
- Does not describe my caregiver very well (0)	4 (30.8%)		
-Does not describe my caregiver well (1)	1 (7.7%)		
-Describes my			

caregiver adequately (2)	4 (30.8%)		
-Describes my caregiver well (3)	3		
-Describes my caregiver very well (4)	(23.18%)		
9. My caregiver tries to see things from my point of view.		1- 4	<b>2.69</b> <b>(1.03)</b>
- Does not describe my caregiver very well (0)	1 (7.7%)		
-Does not describe my caregiver well (1)	0		
-Describes my caregiver adequately (2)	6 (46.2%)		
-Describes my caregiver well (3)	2 (15.4%)		
-Describes my caregiver very well (4)	4 (30.8%)		
10. My caregiver tries to accept me as I am now.		0- 4	<b>3.42</b> <b>(1.65)</b>
- Does not describe my caregiver very well (0)	1 (7.7%)		
-Does not describe my caregiver well (1)	1 (7.7%)		

-Describes my caregiver adequately (2)	0		
-Describes my caregiver well (3)	3 (23.1%)		
-Describes my caregiver very well (4)	8(61.5%)		
<b>Total</b>			<b>2.86 (.894)</b>

Note: The Total score for the scales was derived by the average of mean responses across 10 items multiplied by 13 respondents.

Cursory analysis of ratings by the patient on individual perspective-taking items indicated that there appears to be some underlying discordance in patient perceptions of specific empathic behaviors by the caregiver and the patient (see items #7, 17, and 18). For instance, a comparison of mean scores on Item #17 indicated that patient was in greater agreement that she had engaged in the practice of “believing there are two sides to every story” and that she had engaged in “trying to look at both sides” than her agreement that the caregiver had engaged in the same empathic behaviors.

Across the 10 scaled items on the Empathic Responding Scale, the total score was 2.86 (SD  $\pm$  .894). Of the theoretical range of zero and four on the scale, the total mean score of 2.86 indicates the patient perceived herself as engaging in moderate levels of empathic behaviors, as reported on Long’s (1990) scale. This finding is corroborated by the correlation coefficient ( $\rho = 0.66$ ,  $p = 0.014$ ) between the Perspective-Taking Tool (Patient Perception of Caregiver) and the Empathic Responding Scale. Additional analysis indicated that the highest mean item scores were on the individual items, “My caregiver tries to understand my concerns” ( $m = 3.46$ ) and “My caregiver tries to help me by doing something for me” ( $m = 3.46$ ). The lowest mean item scores were for items “My caregiver tries to experience what I am feeling” ( $m = 1.69$ ) and “My caregiver tries to imagine him/herself in my shoes” ( $m = 1.69$ ).

*Prevalence of Psychological Distress.* The prevalence of patient psychological distress was analyzed through use of the HADS (Zigmond & Snaith, 1983) (see Table 5.8). According to Zigmond and Snaith (1983), the psychiatric ratings for the HADS-A and HADS-D subscale scores are rated according to the following criteria: scores zero to seven are considered non-cases, scores 8 to 10 are considered doubtful cases, and scores

between 11 and 21 are considered clinical cases of anxiety and depression. Nordin et al. (2001) conducted a study aimed at predicting anxiety and depression among cancer patients using the HADS (Zigmond & Snaith, 1983) and considered ratings of 8 or more on the HADS-A and/ or HADS-D subscales as being indicative of a “case” in the identification of psychological distress. For the purposes of this investigation, the same criteria employed by Nordin et al. (2001) were used to determine the psychological distress of patients based on sub-scale scores for anxiety and depression (see Table 5.8.)

According to patient self-report, the mean scores for the HADS-A was 7.9 (SD  $\pm$  4.2) and HADS-D was 4.2 (SD  $\pm$  3.0). The mean global psychological distress score when the HADS-A and HADS-D scores were totaled for this patient population was 12.15 (SD  $\pm$  5.89), with 54% of patients reporting scores of 11 or greater, indicating that they were experiencing psychological distress. Twenty-three percent of participants were ‘non-cases’ and 23.0% were ‘doubtful cases’.

Table 5.8 Hospital Anxiety and Depression Scale Results

Response Items	Frequency	Mean and Standard Deviation (SD)
<b>Range of Scores: 0-3</b>		
<b>HADS-A Subscale</b>		
<b>1.46 (± .877)</b>		
<p><b>1.</b> I feel tense or 'wound-up':</p> <ul style="list-style-type: none"> <li>-Most of the time (3)</li> <li>-A lot of the time (2)</li> <li>-From time to time (1)</li> <li>-Not at all (0)</li> </ul>	<p>2 (15.4%)</p> <p>3 (23.1%)</p> <p>7 (53.8%)</p> <p>1 (7.7%)</p>	
<b>1.38 (± .768)</b>		
<p><b>2.</b> I get a sort of frightened feeling as if something awful is about to happen:</p> <ul style="list-style-type: none"> <li>-Very definitely and quite badly (3)</li> <li>-Yes, but not too badly (2)</li> <li>-A little, but it doesn't worry me (1)</li> <li>-Not at all (0)</li> </ul>	<p>1 (7.7%)</p> <p>4 (30.8%)</p> <p>7 (53.8%)</p> <p>1 (7.7%)</p>	
<b>1.15 (± 1.06)</b>		
<p><b>3.</b> Worrying thoughts go through my mind:</p> <ul style="list-style-type: none"> <li>-A great deal of the time (3)</li> <li>-A lot of the time (2)</li> <li>-From time to time, but not too often (1)</li> <li>-Only occasionally (0)</li> </ul>	<p>2 (15.4%)</p> <p>2 (15.4%)</p> <p>5 (38.5%)</p> <p>4 (30.8%)</p>	
<b>1.15 (± 1.14)</b>		
<p><b>4.</b> I can sit at ease and feel relaxed:</p> <ul style="list-style-type: none"> <li>-Definitely (0)</li> <li>-Usually (1)</li> <li>-Not often (2)</li> <li>-Not at All (3)</li> </ul>	<p>2 (15.4%)</p> <p>3 (23.1%)</p> <p>3 (23.1%)</p> <p>5 (38.5%)</p>	

<p>5. I get a sort of frightened feeling like 'butterflies' in the stomach:</p> <ul style="list-style-type: none"> <li>-Not at all (0)</li> <li>-Occasionally (1)</li> <li>-Quite often (2)</li> <li>-Very often (3)</li> </ul>	<p>6 (46.2%) 5 (38.5%) 2 (15.4%) 0</p>	<p><b>.69 (± .751)</b></p>
<p>6. I feel restless as if I have to be on the move:</p> <ul style="list-style-type: none"> <li>-Very much indeed (3)</li> <li>-Quite a lot (2)</li> <li>-Not very much (1)</li> <li>-Not at all (0)</li> </ul>	<p>1 (7.7%) 7 (53.8%) 1 (7.7%) 4 (30.8%)</p>	<p><b>1.38 (± 1.04)</b></p>
<p>7. I get sudden feelings of panic:</p> <ul style="list-style-type: none"> <li>-Very often indeed (3)</li> <li>-Quite often (2)</li> <li>-Not very often (1)</li> <li>-Not at all (0)</li> </ul>	<p>1 (7.7%) 1 (7.7%) 4 (30.8%) 7 (53.8%)</p>	<p><b>.69 (± .947)</b></p>
<p><b>Overall HADS-A Score</b></p>		<p><b>Range of Scores 0-21</b></p> <p><b>7.9(SD ± 4.2)</b></p>

Response Items	Frequency	Mean and Standard Deviation (SD)
<p><b>HADS-D Subscale</b></p> <p><b>1.</b> I still enjoy the things I used to enjoy:            -Definitely as much (0)            -Not quite as much (1)            -Only a little (2)            -Hardly at all (3)</p> <p><b>2.</b> I can laugh and see the funny side of things:            -As much as I always could (0)            -Not quite so much now (1)            -Definitely not so much now (2)            -Not at all (3)</p> <p><b>3.</b> I feel cheerful:            -Not at all (3)            -Not often (2)            -Sometimes (1)            -Most of the time (0)</p> <p><b>4.</b> I feel as if I am slowed down:            -Nearly all the time (3)            -Very often (2)            -Sometimes (1)            -Not at all (0)</p> <p><b>5.</b> I have lost interest in my appearance:            -Definitely (3)</p>	<p>7 (53.8%)            5 (38.5%)            1 (7.7%)            0</p> <p>8 (61.5%)            4 (30.8%)            1 (7.7%)            0</p> <p>1 (7.7%)            1 (7.7%)            4 (30.8%)            7 (53.8%)</p> <p>2 (15.4%)            3 (23.1%)            8 (61.5%)            0</p> <p>0</p>	<p><b>Range of Scores: 0-3</b></p> <p><b>.54 (± .660)</b></p> <p><b>.46 (± .660)</b></p> <p><b>.69 (± .947)</b></p> <p><b>1.54 (± .776)</b></p> <p><b>.31 (± .630)</b></p>

-I don't take so much care as I should (2)	1 (7.7%)	
-I may not take quite as much care (1)	2 (15.4%)	
-I take just as much care as ever (0)	10 (76.9%)	
<b>6. I look forward with enjoyment to things:</b>		<b>.38 ( ± .650)</b>
-As much as I ever did (0)	9 (69.2%)	
-Rather less than I used to (1)	3 (23.1%)	
-Definitely less than I used to (2)	1 (7.7%)	
-Hardly at all (3)	0	
<b>7. I can enjoy a good book or radio or T.V.:</b>		<b>.31 ( ± .480)</b>
-Often (0)	9 (69.2%)	
-Sometimes (1)	4 (30.8%)	
-Not often (2)	0	
-Very Seldom (3)	0	
		<b>Range of Scores 0-21</b>
<b>Overall HADS-D Score</b>		<b>4.2(SD ± 3.0)</b>
		<b>Range of Scores 0-42</b>
<b>Global Psychological Distress (PD) Score</b>		<b>12.15 ( ± 5.89)</b>

Note: Global Psychological Distress Score was calculated by adding the overall HADS-A score to the overall HADS-D score.

*Research Question #2: Are there associations among patient physical symptom experience, informal caregiver empathic behavior and psychological distress in stage I to stage IV ovarian cancer patients?*

In order to answer research question #2, Spearman's correlation rhos were calculated between ordinal-level variables (see Table 5.9). The investigator explored the existence of significant associations ( $p \leq 0.05$ ) and non-significant trends ( $p < .10$ ) in associations between study variables in this small study sample. The strength of the relationships were based on the following criteria by Hazard Munro (1997):

0.00 – 0.25	little, if any
0.26 – 0.49	low
0.50 – 0.59	moderate
0.70 – 0.89	high
0.90 – 1.00	very high

According to the correlational results, the total physical symptom experience score had a moderately positive correlation with patient depression indicating that the higher the patient self-reports on depression, the more elevated was his or her self-report on symptom experiences. There were no significant associations among total physical symptom experience and patient self-reports on their empathic coping, their perceptions of caregiver empathic coping, and patient anxiety.

Next, the investigator discovered several significant associations with empathic behaviors as self-reported by the patient on the Long (1990) tool. First, there was a moderate, negative association between the patient's self-perception of empathic behaviors and patient anxiety ( $\rho = -.544$ ) ( $p = .054$ ). In other words, the patient reported

Table 5.9 Correlations (Spearman's rho) between patient physical symptom experience, empathic coping behaviors, patient anxiety, and patient depression

	MSAS total	Empathic Coping behaviors (DeLongis)	Empathic Coping behaviors (Long) PTP	Empathic Coping behaviors (Long) PTCG	Anxiety Total	Depression Total
	rho (2-tail) (p)	rho (2-tail) (p)	rho (2-tail) (p)	rho (2-tail) (p)	rho (2-tail) (p)	rho (2-tail) (p)
MSAS total rho (2-tail)	1.000	-.452 .121	-.040 .897	-.326 .277	.200 .512	.563* .045
Empathic Coping behaviors (DeLongis) rho (2-tail)	-.452 .121	1.000	.579* .038	.660* .014	-.689** .009	-.514 .072
Empathic Coping behaviors (Long)PTP rho (2-tail)	-.040 .897	.579* .038	1.000	.735** .004	-.544 .054	-.595* .032
Empathic Coping behaviors (Long) PTCG rho (2-tail)	-.326 .277	.660* .014	.735** .004	1.000	-.586* .035	-.567* .043
Anxiety Total rho (2-tail)	.200 .512	-.689** .009	-.544 .054	-.586* .035	1.000	.229 .452
Depression Total rho (2-tail)	.563* .045	-.514 .072	-.595* .032	-.567* .043	.229 .452	1.000

Note: rho indicates correlation coefficient; 2-tail indicates p-value (significance level).

less empathic coping behaviors towards her caregiver when she experienced more anxiety. Second, there was a moderate, negative association between the patient's self-report of empathic coping behaviors on Long's (1990) tool and patient depression ( $\rho = -.595, p = .032$ ). In other words, as the patient's depression increased, she reported less empathic coping behaviors towards her caregiver. Third, the investigator found a significantly high or strong, positive association between the patient's self-report of and the patient's perception of caregiver empathic behaviors as captured on the Long (1990) tool ( $\rho = .735, p = .004$ ). This means that the patient's perception of empathic behaviors exhibited by oneself and his or her caregiver corresponded closely. This correlation between patient self-perception of and perception of the caregiver's empathic behaviors as captured on the DeLongis (1990) tool was corroborated ( $\rho = .66, p = .014$ ). The investigator then explored associations between patient perceptions of caregiver empathic coping behaviors as captured by the Long (1990) tool, and patient self-reports of anxiety and depression. Significantly moderate, negative associations were found between patient perceptions of caregiver empathic coping behaviors and patient self-report of anxiety ( $\rho = -.586, p = .035$ ) and depression ( $\rho = -.567, p = .043$ ) respectively. In other words, when the patient perceived less empathic coping behaviors by the caregiver, the patient experienced more anxiety and depression. The moderately negative association between patient anxiety and patient perception of caregiver empathic behaviors as captured by the DeLongis (1990) tool was supported ( $\rho = -.689, p = .009$ ). In summary, the results of this correlational analysis indicates that there were significant associations between patient physical symptom experience and patient depression.

There were significant negative associations between the patient's perception of informal caregiver empathic behaviors and patient depression and anxiety, respectively. The patient's physical symptom experiences were not associated with informal caregiver empathic behaviors.

Supplemental analyses were also conducted to offer potential insights on associations between the patient's sociodemographic characteristics and empathic coping behaviors, physical symptom experiences, and psychological distress (see Table 5.10). According to this supplemental analysis, there were several significant associations involving patient age. First, there was a strongly positive association with the patient's perception of the caregiver's empathic responding and patient age. In other words the older the patient, the more he or she perceived increased empathic behaviors by the caregiver. Second, a strongly negative association occurred where the older the patient, the less anxiety she experienced. Other significant associations occurred involving the patient's perception of the caregiver's knowledge of their physical symptoms as captured on the patient demographic tool regarding items on the caregiving relationship.

First, there were strongly positive associations between the caregiver's knowledge of the patient's physical symptoms, and the patient's perceptions of the caregiver's empathic behaviors as captured on both the DeLongis (1990) and Long (1990) tools. In other words, the more the patient perceived that the caregiver engaged in empathic behaviors, the more the patient reported the caregiver knew his or her physical

**Table 5.10 Correlations** (Spearman's rho) between patient sociodemographic characteristics and empathic coping behaviors, patient physical symptom experiences, patient anxiety, and patient depression

	Level of Education rho (p)	Patient Age rho (p)	Annual Family Income rho (p)	Length of time caregiver caring for pt rho (p)	Caregiver knowledge of patient physical symptoms rho (p)	Perception of cg knowledge of emotions rho (p)	Degree of contact b/w pt and cg rho (p)
MSAS tot rho (2-tail) N	-.106 .731 13	-.209 .493 13	.041 .910 10	-.136 .659 13	-.285 .345 13	-.529 .063 13	-.114 .710 13
Delongis rho (2-tail) N	-.077 .802 13	.690** .009 13	.303 .395 10	.468 .107 13	.655* .015 13	.504 .079 13	.086 .781 13
Long_PTP Correl coef rho (2-tail) N	-.367 .218 13	.442 .131 13	.443 .200 10	.488 .091 13	.508 .076 13	.318 .289 13	-.228 .453 13
Long CG Correl coef rho (2-tail) N	-.069 .824 13	.476 .100 13	.428 .217 10	.224 .461 13	.771** .002 13	.737** .004 13	.143 .641 13
HADS AT Correl coef rho (2-tail) N	.255 .401 13	-.708** .007 13	-.282 .429 10	-.458 .116 13	-.584* .036 13	-.249 .412 13	-.086 .779 13
HADS DT rho (2-tail) N	.254 .402 13	-.296 .326 13	.132 .716 10	-.407 .168 13	-.421 .152 13	-.514 .072 13	.145 .636 13

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

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

Tot = total score

DT = Depression Total

AT = Anxiety Total

Long PTP= Patient Self Perception

Long PTCG= Patient Perception of Caregiver

rho: Correlation Coefficient

(2-tail): p value significance

symptom experiences well. A strongly positive association was also revealed between the patient's perception of the caregiver's empathic behaviors with him or her, as captured on the Long (1990) tool and the patient's report of the caregiver's knowledge of his or her emotions. In other words, the more the patient perceived the caregiver to have engaged empathically with him or her in their relationship, the more the patient felt the caregiver knew his or her emotions. Of note, there was no significant association found between the patient's report on the caregiver's knowledge of patient emotions and the caregiver's empathic behaviors as captured on the DeLongis (1990) tool, although the association did lean toward a level of significance ( $p = 0.079$ ). A final supplemental result was that the more the patient perceived that the caregiver knew his or her physical symptom experiences, the less anxiety the patient reported on the HADs scale. Overall no sociodemographic variables that were tested were significantly associated with patient physical symptoms, patient self-report on empathic coping behaviors, and patient depression.

According to the literature review in Chapter Two, there was evidence that suggested exploration of other demographic factors (e.g. marital status, ethnicity, cultural background, religiosity, treatment history, current treatment, the type and stage of ovarian cancer, and occupational status) would be warranted. However, these were not analyzed in light of the study's small sample size and limited variability of these variables across the participant sample.

*Research Question #3: What is the concurrent validity of the Empathic Responding Scale (O'Brien & DeLongis, 1990) compared with the Perspective-Taking Scale (Long, 1990)?*

In order to answer research question #3, a Pearson's correlation coefficient  $r$  was calculated between respective total scores on the Empathic Responding Scale (Delongis, 1990) and the Perspective-Taking Tool (Long, 1990) that captured the patient's perception of the caregiver's empathic responding behaviors. The analyses revealed that the Empathic Responding Scale was positively correlated with the Perspective-Taking Tool PTCG (Patient Perception of Caregiver) ( $r = .545, p = .054$ ). In addition, and as a basis of comparison, the Perspective-Taking Tool PTP (Patient Self-Perception) was also correlated with the Empathic Responding Scale ( $r = .728, p = .005$ ).

The correlational analyses results indicate that there was only a moderate but significant degree of concurrent validity between the two scales that captured the patient's perception of the caregiver's empathic behaviors (i.e., Empathic Responding Scale and the Perspective-Taking Tool PTCG). However, there was a strong correlation between the Empathic Responding Scale (i.e., captured the patient's perception of the caregiver's empathic behaviors) and the Perspective-Taking Tool that captured the patient's self-perception of empathic behaviors. It is difficult to decipher why these results occurred. However, it is possible that a more strong correlation between the Empathic Responding Scale and the Perspective Taking Scale on caregiver empathic behaviors would be revealed in a larger study sample. Further testing is warranted to lend more convincing evidence that supports the concurrent validity between the Empathic Responding Scale and the Perspective-Taking Tool PTGC that capture the caregiver's empathic behaviors as perceived by the patient.

### *Summary*

Descriptive analyses of the data allowed the investigator to describe the typical characteristics of patient participants in this study. The typical patient participant was 58 years of age, English speaking, married, identified themselves as being European or Canadian in ethnic origin, Catholic, United Church (Protestant), or Buddhist in religiosity, unemployed, retired, or on medical leave, and not receiving nursing service in the home. In addition, the majority of patient participants had either completed or partially completed high school, college, or university level education, worked in management, and reported an annual family income as being greater than or equal to \$31,000.00. In terms of medical characteristics, the typical patient was diagnosed with stage III epithelial ovarian cancer more than 19 months previous to the time of the interview, not receiving current treatment, and had received surgery and chemotherapy in the past.

Inferential analyses of the data yielded a number of important results in relation to the respective study questions. For research question #1 concerning the prevalence of symptoms in ovarian cancer patients, the most prevalent physical symptoms reported were lack of energy (61.5%), sweats (53.8%), and numbness/tingling in the hands and/or feet (46.2%). The mean number of patient symptoms was 6.53 (SD  $\pm$  5.92). From the data set, there appears to be a lack of association between the underlying dimensions of frequency, severity, or distress, meaning that reports of frequently occurring or severe symptoms did not mean that those symptoms were highly distressing to the patient. For example, 75.0% of patients reported experiencing frequent and severe lack of energy. However, only 25% were highly distressed by this symptom. Conversely, symptoms such

as vomiting and dizziness that were reported as being infrequent but severe (100%) caused the most distress (100%). The patient's self-perception and perception of caregiver empathic behaviors were highly congruent and strongly associated indicating high levels of empathic behaviors in the caregiving relationship. The prevalence of psychological distress was high with 54 % of the patient self-reports on psychological distress meeting the criteria for having psychological distress, predominantly manifested by anxiety.

For research question #2 concerning the relationships among patient physical symptom experiences, empathic coping behaviors, and patient psychological distress, a number of significant findings were revealed. Several significant associations were found among patient psychological distress, empathic coping behaviors, and patient physical symptom experiences. For instance, patient physical symptom experiences were positively correlated with patient depression. However there was no significant association found with empathic coping behaviors. The patient's perception of his or her caregiver's empathic behaviors were negatively correlated with patient self-reports on anxiety and depression. Similarly, the patient's perceptions of one's own empathic behaviors with the caregiver were negatively correlated with the patient's self-report on anxiety and depression. Supplemental analyses were also conducted to explore additional associations involving the patient's sociodemographic characteristics, and the patient's caregiving relationship with patient physical symptom experiences, empathic coping behaviors, and patient psychological distress. The investigator found that the patient's age was positively associated with the patient's perception of the caregiver's empathic behaviors. However, patient age was negatively correlated with the patient's self-report

of anxiety. The patient's perception of the caregiver's empathic behaviors was positively associated with the patient's perception of the caregiver's level of knowledge about the patient's physical symptoms, and patient emotions.

For research question #3, in terms of determining the concurrent validity between Delongis' (1990) 10-item Empathic Responding Scale (that captured the patient's perception of the caregiver's empathic behaviors) and Long's (1990) 20-item Perspective-Taking Tool (PTCG) on caregiver empathic behaviors as reported by the patient, the investigator found only a moderate correlation ( $r = 0.55$ ). Interestingly, the correlation between the Empathic Responding Scale and the Perspective-Taking Tool (PTP) on patient empathic behaviors was strongly correlated ( $r = 0.73$ ).

## CHAPTER SIX

### Discussion

#### *Introduction*

One of the aims of this pilot study was to provide insight into the physical and psychological status of ovarian cancer patients. However, due to the limited number of patients who participated ( $n = 13$ ), caution is warranted in terms of interpreting the results of this pilot work. The information gleaned from this pilot study can be considered a preliminary foundation upon which to build further knowledge of ovarian cancer patient psychological distress in a larger study. Overall, this study was guided by the concepts of patient physical symptom experiences, empathic coping behaviors, and patient psychological distress. The theoretical framework entitled *Stress, Appraisal and Coping* by Lazarus and Folkman (1984) provided the foundation for conceptualization of this study. A discussion of results for three research questions will follow, including a comparison of this study's results with findings described in related literature. Following a discussion of the study's limitations, clinical practice implications and recommendations for future research are offered.

#### *Representativeness of Study Patient Sample*

Ninety-two percent of patients reported having recurrent epithelial ovarian cancer and the mean patient age was 58.7 years. This study's sample of ovarian cancer patients appears to be a reasonable representation of ovarian cancer patients as supported by related literature that described epithelial ovarian cancer as the most commonly diagnosed ovarian cancer that rarely occurs in women under 40 years of age (Hoskins et al., 2004). Furthermore, according to the National Cancer Institute of Canada (2006),

the peak incidence for ovarian cancer is between 50 to 60 years of age which is consistent with the mean patient age in this study. Kornblith et al (1995) conducted an investigation on the quality of life of women with ovarian cancer (n=151) and reported the mean age of participants as 54 years. The majority of participants reported being married or living common-law (84.6%) and a large number (38.5%) held a college or graduate degree. This demographic information coincides with related study reports on ovarian cancer patient demographics. According to the study conducted by Kornblith et al (1995) the majority of study participants were married (64%), well educated (40%) had graduated from college or held an advanced degree, and 86% of patients had either stage III or stage IV ovarian cancer. The majority of participants (84.6 %) in this study were diagnosed with Stage III or Stage IV ovarian cancer, which coincides with widely reported demographic data that described over 70% of ovarian cancers are diagnosed at Stage III or Stage IV (Fishman et al., 2005; Yawn et al., 2004).

All patient participants identified English as being the language spoken at home, with a major portion of participants having identified themselves as being of European or Canadian descent. A small minority of patients identified themselves as being of Middle-Eastern descent. This study's finding has limited generalizability as this study sample does not represent ovarian cancer patients who do not speak English or are members of other cultural or ethnic origins. Although religiosity was widely varied, the majority of participants identified themselves as being of the Catholic faith, which also limits generalizability of findings to patients of other religious orientations.

*The Caregiving Relationship and Lazarus and Folkman's Stress, Appraisal, and Coping Theory*

The majority of participants reported that their caregivers both always and frequently helped them to cope with the physical as well as emotional aspects of their medical condition and were able to speak with their caregivers openly about both aspects of their illness. Reports of whether participants felt that their caregivers understood their thoughts and feelings regarding physical and emotional aspects of their illness were widely varied, with some participants reporting that their caregiver did not understand very well or not at all. This is important information according to Long (1990) who suggested that one partner's understanding of the needs, interests, and desires of the other is positively related to marital adjustment and coping. The investigator determined it is plausible that when the patient perceives the informal caregiver does not engage in empathic behaviors, the patient's personal resources decrease, and the physical symptom experience may be appraised by the patient as more threatening. This can result in psychological distress. Significant findings regarding these relationships will be discussed further as guided by Lazarus and Folkman's theory.

To recap a previous discussion of the Stress, Appraisal, and Coping Theory developed by Lazarus and Folkman (1984), this theory was adapted to conceptualize associations between the empathic behaviors of informal caregivers, a dimension of social support, and patient psychological distress and patient physical symptoms experienced by ovarian cancer patients (Figure 1). According to Lazarus and Folkman, when an individual is confronted with a stressor (e.g., a physical symptom experience), he or she appraises the situation as either threatening, or benign, which ultimately influences how this individual will cope with the situation. This appraisal is influenced by personal and environmental resources. O'Brien and DeLongis (1990) proposed that

empathic or relationship-focused coping strategies, that involve perspective-taking, may be a personal resource that exists within the caregiving context that influences how the patient copes with, as in the current study, physical symptom experiences and psychological distress. This study's focus on the social support (personal resource) component of Lazarus and Folkman's (1984) model is an attempt to at least partially explain the relationship among physical symptom experience, perceived empathic behavior of caregivers, and psychological distress. The following discussion of study findings is based upon the preceding premises highlighted in the Stress, Appraisal, and Coping Theory (Lazarus & Folkman, 1984).

*Research Question #1 Prevalence of Physical Symptom Experience, Empathic Informal Caregiver Behavior and Psychological Distress*

*Prevalence of physical symptom experience.* Physical symptoms were prevalent in this patient sample. The most prevalent physical symptoms reported by this study's sample of patients were lack of energy, sweats, and numbness/tingling in the hands and/or feet. Interestingly, as evidenced by the data set, the underlying dimensions of frequency, severity, and distress did not appear to be associated, indicating that the most frequently occurring or severe symptoms may not be highly distressful to the patient. The high prevalence of lack of energy in this sample is consistent with other studies involving cancer patients (See Table 6.1). In a study by Portenoy, Kornblith, et al. (1994) aimed at quantifying the pain in ovarian cancer patients, lack of energy was also found to be the most prevalent symptom. In another study conducted by Portenoy, Thaler, et al. (1994) that measured symptoms in a mixed cancer patient cohort (including ovarian cancer patients), lack of energy was also rated as the most prevalent symptom. Of note is that

Table 6.1. Comparison of reported symptoms across related studies

	Symptom Prevalence in Ovarian Cancer Patients Present Study	Symptom Prevalence in Ovarian Cancer Patients Portenoy, Kornblith, et al (1994)	Symptom Prevalence in Mixed-Cancer Patients Portenoy, Thaler, et al (1994)
Pain	38.5%	61.8%	63.1%
Lack of Energy	61.5%	68.6%	73.4%
Cough	23.1%	25.3%	29.4%
Dry Mouth	38.5%	45.6%	55.3%
Nausea	23.1%	35.6%	44.7%
Feeling Drowsy	38.5%	45.3%	59.7%
Numbness/Tingling in Hands/Feet	46.2%	42.7%	36.4%
Feeling Bloating	30.8%	34.7%	38.7%
Problems with Urination	7.7%	7.3%	15.6%
Vomiting	7.7%	13.3%	21.1%
Shortness of Breath	38.5%	18.7%	22.9%
Diarrhea	15.4%	20.8%	23.9%
Problems with Sexual Interest or Activity	0	17.6%	23.3%
Itching	7.7%	22.3%	27.2%
Sweats	53.8%	N/R	N/R
Dizziness	7.7%	16.2%	23.4%
Difficulty Swallowing	7.7%	5.4%	10.6%
Lack of Appetite	23.1%	28.4%	44.5%
Mouth Sores	15.4%	8.1%	12.9%
Change in the way food tastes	30.8%	25.7%	37.2%
Weight Loss	15.4%	18.5%	27.0%
Constipation	38.5%	28.6%	33.6%
Swelling of Arms or Legs	15.4%	18.9%	27.5
Hair Loss	7.7%	26.4%	17.1
"I don't look like myself"	30.8%	35.8%	28.2%
Changes in Skin	38.5%	N/R	N/R

Note: N/R = not rated

although sweating was one of the most prevalent symptoms in this sample, it did not cause the most distress, nor was it rated as most distressing in studies by Portenoy, Thaler, et al. (1994).

Interestingly, the differences in the prevalence of pain reported in the current study (38.5%) and previous studies by Portenoy, Kornblith, et al. (1994) (61.8%) and Portenoy, Thaler, et al. (1994) (63.1%) are notable. Although this study's sample size of 13 was small and may have contributed to differences in pain ratings between studies, the difference in pain ratings can be influenced by other factors that warrant discussion. For instance, Portenoy, Kornblith, et al. (1994) found that 'inpatient status' was a significant predictor of pain in a sample consisting of 73.5% (111 of 151) ovarian patients. This was also the case in a study conducted by Portenoy, Thaler, et al. (1994) where they developed the MSAS in a heterogeneous sample consisting of 56% inpatients that were diagnosed with cancer. All of the patients who participated in this study were outpatients living in the community, which perhaps partially accounted for the lower prevalence of pain.

Furthermore, the focus of Portenoy, Kornblith, et al.'s (1994) study was on pain measurement and all patients received a pain package aimed at focusing on experienced pain by ovarian cancer patients. This study's method might have biased patient responses to other symptoms as pain was highlighted as the primary investigative issue. The MSAS was administered with a number of other instruments measuring pain (e.g., the MSAS pain assessment cards, the Brief Symptom Inventory pain interference items, and other items that clarified the location and frequency and duration of pain).

Another study finding that warrants further attention is that the frequency, severity, and distress of symptoms did not appear to be related. Based on this study's reports by patients, lack of energy was reported as being the most prevalent symptom (61.5%) and occurring with high frequency (75%) and severity (75%). However, only 25% of patients were highly distressed by it. Alternatively, nausea was a low prevalence symptom (23.1%) that caused significant distress (66.7%). This finding may impact the actual interpretation of the prevalence of a symptom as it can be stated that perhaps certain symptoms were not highly prevalent as they were not causing the patient distress. This study's sample of patients also revealed that the presence of feeling bloated, vomiting, itching, and dizziness, swelling of arms and legs, and diarrhea also caused the most distress to patients in comparison to other, more prevalent symptoms such as lack of energy and sweats that did not appear to be causing a great deal of distress to patients. Prevalence or distress levels of these symptoms were similar across studies by Portenoy and colleagues' (1994) studies and the current study, but the distress arising from these symptoms were slightly elevated in the mixed cancer study Portenoy, Thaler, et al. (1994). This could be a result of Portenoy, Thaler, et al.'s study sample of patients who were undergoing treatment at the time of the investigation. The type of cancer may have played a part in the prevalence of diarrhea in the mixed-cancer cohort as that study sample included patients diagnosed with colorectal cancer.

The prevalence of lack of appetite and dry mouth was low in this study's patient sample and in the study by Portenoy, Kornblith, et al. (1994). The prevalence of these two symptoms was higher in the mixed cancer study conducted by Portenoy, Thaler, et al. (1994) which could be partially explained by treatment side effects. Problems with

urination, difficulty swallowing, and mouth sores caused the least amount of distress in the present study and were of low prevalence in both studies conducted by Portenoy, et al. (1994). Interestingly, this study's sample of ovarian cancer patients did not report the presence of problems with sexual interest/activity. This finding contrasts with results by Portenoy, Kornblith, et al. (1994) and Portenoy, Thaler, et al. (1994) who reported the prevalence of problems with sexual activity as 17.6% and 23.3 % respectively. A retrospective study conducted by Fitch et al. (2001) aimed at assessing physical symptoms of older (over the age of 69 years) women with ovarian cancer (n=146) revealed that women experienced on average 5.2 symptoms since diagnosis and that the most common symptoms reported were side effects (54%), fear of recurrence (45%), bowel difficulties (43 %), and difficulty sleeping (36%).

The mean number of reported symptoms in the present sample was 6.53 that compares with a mean of 10.2 symptoms in the ovarian cancer study by Portenoy, Thaler, et al. (1994) and 5.2 symptoms in the study by Fitch et al. (2001). The difference in numbers between this study and the study by Portenoy, Thaler, et al. (1994) is difficult to explain as, other than this study's small sample size, the sample characteristics of both studies were similar (age, stage of cancer, type of treatment, recurrence and number of cycles of chemotherapy). The differences in the mean scores between the present study and the one conducted by Fitch et al. (2001) could be due to a variety of factors including the instrument used to capture physical symptoms (a general quality of life questionnaire consisting of 54 questions), as well as Fitch et al.'s study targeted women over the age of 69 years.

*Prevalence of Empathic Informal Caregiver Behavior.* Informal caregiver empathic behavior was moderately prevalent in this sample. The total mean scores for the PTP and PTCG scales were 2.74 (SD  $\pm$  .589) and 2.46 (SD  $\pm$  .596) respectively. These results are quite comparable, indicating a certain degree of concordance between patient perception of her empathic behavior and patient perception of her informal caregiver's empathic behavior. According to Long (1990), correlated results may reveal one partner's sensitivity to the needs, interests, and desires of the spouse. From this data set, it appears that the ovarian cancer patient is not only sensitive to her informal caregiver's needs and desires, but also perceives that her caregiver is sensitive to her needs and desires. To further corroborate the above, the association between the two Perspective-Taking Tools was 0.74 in this study. This finding indicates that the patient's perception of her own empathic behaviors and the caregiver's empathic behaviors were indeed similar. In other words, the patient and caregiver appeared to engage in a reciprocal, supportive relationship where the patient felt that they could empathically communicate, at least in accordance with the patient's perception of empathic behaviors in the caregiving context. The importance of reciprocal cancer-related communication in relation to empathic behavior has been reported by Kornblith et al. (2006) who conducted a study with cancer patients and their spouses. According to Kornblith, et al., those patients who were able to communicate openly with their caregivers were able to do so due to the perception of empathy from their partners, and consequently reported less psychological distress. The results of this study are also significant in relation to Norton et al.'s (2005) suggestion that the relationship between psychological distress and physical symptom experience is likely influenced by the social support patients receive from family or friends.

*Prevalence of Psychological Distress.* The prevalence of moderate to severe psychological distress in the present sample was 54%. This rate is similar to psychological distress rates reported by Portenoy, Kornblith, et al (1994) involving ovarian cancer patients. However, the current study's rate of psychological distress is higher than rates reported from other studies (see Table 6.2). Factors that may influence the reporting or existence of prevalence rates across studies include the timing of data collection, the method of data collection, and study sample size.

Hipkins et al. (2005) conducted a prospective study with ovarian cancer patients (N=63) using the HADS in order to determine psychological distress (anxiety and depression) in the three month period after chemotherapy, and to identify factors that might predict psychological morbidity. The patients in Hipkins et al.'s study were assessed for anxiety, depression, stage of disease and their perception of emotional support. The results of the study indicated that women with ovarian cancer experienced clinically significant psychological morbidity; however the disease stage and patient performance status were not associated with a worse psychological outcome for patients. The results of the current study are consistent with other studies involving ovarian cancer patients, regardless of measurement instruments (see Table 6.3) and with prevalence of psychological distress ranging from 23% to 62% (see Table 6.2).

*Research Question #2 - Associations among physical symptom experience, informal caregiver behavior and psychological distress*

The analyses of pilot data for research question #2 revealed several significant findings that provide tentative support for the relationships that were postulated in Lazarus and Folkman's (1984) theory. First, the patient's physical symptom experiences

were not significantly correlated with measures that captured caregiver empathic behaviors. However, there was a trend that indicated as the patient's physical symptom experiences decreased, the patient perceived increased empathic behaviors by the caregiver. This type of association has been previously reported as significant in work by Portenoy, Thaler, et al. (1994). It is possible that the investigator would have found a significant result in a larger study sample.

Second, the patient's physical symptom experiences were shown to be positively associated with psychological distress in this study sample. This finding indicates that when patients reported more elevated physical symptom experiences, they also experienced more psychological distress. This study finding is supported by similar findings in the ovarian cancer-related literature. For example, Bodurka-Bervers et al. (2000) studied psychological distress (including anxiety and depression), and quality of life in patients with 244 epithelial ovarian cancer patients and found a negative relationship between psychological distress and quality of life. This also consistent with findings reported by Kornblith et al. (1995), that is, as the patient's psychological distress increased, the patient's physical symptom experiences increased, and patient quality of life was diminished.

Table 6.2 Comparison of Total Psychological Distress in Ovarian Cancer Patients Across Studies.

Source	Prevalence of Psychological Distress in Ovarian Cancer Patients	Measure of Psychological Distress	Type of Cancer	Stage of Cancer	Treatment
Present Study	54%	HADS	Epithelial	1-4	Yes
Bodurka-Bevers et al. (2000)	29%	CES-D STAI	Epithelial	1-4	Yes
Hipkins et al. (2005)	27%	HADS	Epithelial	1-4	Yes
Kornblith et al. (1995)	33%	MHI	Unspecified	1-4	Yes
Norton, Manne, et al. (2004)	23%	MHI BDI	Unspecified	1-4	Yes
Norton, Manne, et al. (2005)	30 to 50%	MHI	Unspecified	1-4	Yes
Portenoy, Kornblith, et al. (1994)	62%	MSAS	Unspecified	1-4	Yes

Note: CES-D or Center for epidemiologic studies-Depression Scale (Radloff, 1977), MHI or Mental Health Inventory (Veit & Ware, 1983), STAI or State-Trait Anxiety Inventory (Spielberger, 1970)

Table 6.3. Comparison of HADS psychological distress scores

HADS	Psychological Distress in Ovarian Cancer Patients: Current Study (n =13)	Psychological Distress in Ovarian Cancer Patients: Hipkins et al (2005) (n = 141 )
HADS-A Cases	31%	38%
HADS-D Cases	0.0%	33%
HADS Total Cases (HADS-A +HADS-D)	54%	Not Reported

Note: HADS-A or Hospital Anxiety and Depression Scale-Anxiety Subscale.  
HADS-D or Hospital Anxiety and Depression Scale- Depression Subscale.  
Scoring of 0-7 = non case  
Scoring of 8-10 = doubtful case  
Scoring 11-21 = clinical case

Third, in this study it was found that the patient's perception of empathic behaviors by the informal caregiver was negatively associated with psychological distress in this sample. In other words, that as the patient's perception of empathic caregiver behaviors increased, the less psychological distress was experienced by the patient. Hipkins et al. (2005) also conducted a study aimed at assessing the quality of life of ovarian cancer patients (n=63) and found that low levels of perceived emotional support were significantly associated with increased psychological distress. Jefferies (2002) also described a high prevalence of psychological distress in ovarian cancer patients and that emotional and social supports were extremely important in light of their positive effects on quality of life and the reduction of patient psychological distress.

To recap, several significant findings lend tentative support toward relationships among patient physical symptom experiences, the empathic behaviors of informal caregivers, and patient psychological distress as guided by Lazarus and Folkman's (1984) theory. These findings are important as they speak to the impact of caregiver empathic behaviors on not only the patient's ability to obtain optimal support from their informal caregivers, but also the manner in which the informal caregiver responds to patient physical and emotional concerns. According to Hipkins et al. (2005), the degree of emotional support represents a measure of the emotional quality of a key interpersonal relationship for ovarian cancer patients. The lack of emotional support from key supportive individuals may inhibit the expression of patient concerns about the physical disease and result in maintained or exacerbated psychological distress by patients. This may translate into the patient's appraisal of the disease as being more threatening, resulting in psychological distress. Hipkins et al. (2005) also suggested that this may

represent a reciprocal phenomenon. In other words, when the patient with high physical and psychological distress behaves in a manner that discourages support from their relatives, this may result in the patient's perception of a lack of support. As part of a vicious cycle, the patient may then experience compounded physical and psychological distress. According to Zabora et al. (2001), the patient's cancer experience is significantly impacted by psychosocial support as most patients derive critical support from their spouses in order to problem-solve, as well as develop a buffer against the multiple sources of stress resulting from a cancer diagnosis.

Supplemental analysis revealed several significant associations involving the research variables and patient demographic characteristics that also warrant further discussion. First, there was a strongly positive association with the patient's perception of the caregiver's empathic behavior and patient age. In other words the older the patient, the more he or she perceived increased empathic behaviors by the caregiver. This is consistent with Long's (1990) notion that as relationships mature, perspectives of empathic behavior of the spouse also change. Second, a strongly negative association between patient age and psychological distress was found, where the older the patient, the less anxiety he or she experienced. Merluzzi and Martinez-Sanchez (1997) reported that increasing age is associated with greater adjustment, possibly due to older people being better adjusted psychologically in their close relationships than younger people.

Other significant associations occurred involving the patient's perception of the caregiver's knowledge of their physical symptoms as captured on the patient demographic tool regarding items on the caregiving relationship. First, there were strongly positive associations between the caregiver's knowledge of the patient's physical

symptoms, and the patient's perceptions of the caregiver's empathic behaviors as captured on both the DeLongis (1990) and Long (1990) tools. In other words, the more the patient perceived that the caregiver engaged in empathic behaviors, the more the patient reported the caregiver knew her physical symptom experiences well. A strongly positive association was also revealed between the patient's perception of the caregiver's empathic behaviors with her, as captured on the Long (1990) tool and the patient's report of the caregiver's knowledge of her emotions. In other words, the more the patient perceived the caregiver to have engaged empathically with her in their relationship, the more the patient felt the caregiver knew her emotions. This association between empathic behavior and feeling understood regarding the cancer experience is supported by literature. Pistrang, et al. (1997) conducted an analysis of breast cancer patient's conversations with their partners and reported that patients who perceived low levels of empathic behavior from their partners felt misunderstood and consequently had a difficult time with expressing their needs. Pistrang et al. (1997) further reported that those partners who were rated as 'unhelpful' were also characterized by a lack of empathic behavior. This finding is significant as those patients who feel their partners engage in empathic behavior may be able to communicate their physical or psychological symptoms with ease compared with patients who feel their partners to not engage in empathic behaviors. Cancer-related communication has been studied by Kornblith et al.(2006) who reported that patients and caregivers alike reported lower levels of psychological distress when they were able to communicate with their partner regarding the cancer experience.

One thing to note is that during the interviews, one consistent theme emerged. Most participants revealed that their informal caregiver (usually their spouse) was largely

in denial of their cancer and possible early mortality. Also, most participants revealed because of this they did not express the full extent of their physical or psychological distress (more so for psychological distress) out of consideration for their spouse. This information is significant. The patients' knowledge of the denial exhibited by the informal caregiver in addition to her own realization of her lack of disclosure may have played a role in her perception of the caregiver's ability to exhibit empathic behaviors, and ability to understand and know her emotions and physical symptoms. The acceptance of this denial indicates the patient's awareness that it is part of a protective mechanism and may impact the extent to which the patient is able to openly share her emotions with her caregiver. This may signify a reciprocal issue because if the patient herself isn't forthcoming in the relationship in order to protect the caregiver, the caregiver may be unaware of her emotional or physical needs. This finding has been reported in other studies and indicates that the sample may be representative in this area. For instance, Pistrang et al. (1997) conducted a study with breast cancer patients and reported that many women wanted to protect their partner from worrying and that they felt he could not cope with their thoughts and feelings. Although a certain level of denial may act as a protective mechanism, it may be significant as the lack of communication may impact both the patient and their caregiver. According to Kornblith et al.'s (2006) study involving cancer patients and their partners aimed at evaluating cancer-related communication (n=324), patients who were able to communicate openly with their partners experienced lower levels of psychological distress. Kornblith et al. (2006) also reported that partners who were able to communicate with patients also exhibited lower

levels of psychological distress. Participants in Kornblith et al.'s (2006) study recommended that clinicians assume a role in improving cancer-related communication.

Interestingly, although patients consistently expressed that their caregivers were in denial of the reality of their cancer, they did not express this until later in the interview, during the Perspective-Taking tools rather than during the Empathic Responding Scale. The investigator felt that this was possibly due to the increased level of comfort later in the interviews due to a longer period of time spent speaking with the investigator. Also, it should be noted that the patients consistently volunteered information regarding caregiver denial and that the investigator did not inquire about caregiver denial. This is significant as it speaks to the possible necessity of incorporating a measure of caregiver denial in future studies that may provide further insight into patient perception of empathic behaviors as well as patient perception caregiver knowing her emotions and physical symptoms.

In summary of this discussion, significant associations were found between patient physical symptom experiences, the empathic behaviors of informal caregivers and patient psychological distress that provide tentative support toward Lazarus and Folkman's (1984) theory. Other sociodemographic and illness related variables (e.g., marital status, ethnicity, cultural background, religiosity, treatment history, current treatment, the type and stage of ovarian cancer, and occupational status) were not analyzed in light of the study's small sample size and limited variability of these variables across the participants. Other than patient age, the patient's level of education, annual family income, and length of caregiving time were not significantly associated with patient physical symptoms, patient self-report on empathic coping behaviors, or

patient psychological distress. These results have important clinical implications that will be discussed further below.

*Research Question #3: Concurrent Validity of the Empathic Responding Scale compared with the Perspective Taking Tool*

The primary purpose for exploring the concurrent validity of the Empathic Responding Scale by DeLongis (1990) (see Appendix E) with the Perspective-Taking Tool by Long (1990) (see Appendices G & H) was to establish the validity of employing a brief tool to capture the empathic behaviors of informal caregivers as perceived by cancer patients. Lobchuk (2001) previously employed the 20 item Dyadic Perspective-Taking Tool in her dissertation work with 98 cancer patients and their informal caregivers. However, Lobchuk found the tool had prompted limited variability in participant responses, where patient and caregiver participants tended to respond positively to items on the Dyadic Perspective-Taking Tools. A ceiling effect was identified that might have been in relation to the burden of having to complete a lengthy tool where the wording was confusing to participants who required frequent clarification of the items by the research nurse. In addition, while the Dyadic Perspective-Taking Tool was previously employed with cancer patients and their caregivers, the Empathic Responding Scale had been employed only with wives of patients with Alzheimer's disease (Kramer, 1993).

A comparison of the item content of the 10 Likert-type questions on the Empathic Responding Scale with 20 Likert-type items on the Dyadic Perspective-Taking Tool suggested that the Empathic Responding Scale had good face validity in terms of capturing similar domains of empathic behavior by informal caregivers as perceived by

the patient. Furthermore, DeLongis (1990) defined empathic behavior as a multidimensional determinant of social behavior that drives caring and supportive actions between the patient and the informal caregiver. In the current study, Empathic behavior involves efforts by the patient and informal caregiver to engage in perspective-taking in order to vicariously experience the world as the other person sees it and to formulate one's own associations to the symptom event. Empathic behaviors also involve the patient's and the caregiver's efforts to interpret psychological states that underlie the other person's verbal and non-verbal communication, and to respond sensitively to the other person out of a state of concern or to express caring or understanding in an accepting, nonjudgmental, emotionally validating manner.

Long (1990) defined dyadic perspective-taking as a process whereby one person attempts to understand the experience or point of view of their partner by putting oneself in his or her partner's position. These definitions suggested to the investigator that both tools captured similar conceptualizations of empathic behaviors by partners in close relationships, although DeLongis called these behaviors "empathic responding", and Long named the same behaviors "dyadic perspective-taking" activities. Both tools are pencil-and paper instruments that contained Likert-type items which capture behavioral and cognitive activities that depict the empathic process. While the Perspective-Taking Tool consists of two scales to be completed respective to the perceptions of the individual and the relational partner about the other's empathic behaviors, the Empathic Responding Scale was developed to capture only the individual's perception of their partner's empathic responding towards them. For the purpose of this study, the investigator obtained permission from Anita DeLongis (personal communication, December 1, 2005),

the tool's developer, to revise the Empathic Responding Scale to also capture the patient's self-perception of empathic behaviors towards the informal caregiver.

Together, the investigator and Dr. Lobchuk deemed that exploring the benefits of employing a brief instrument was warranted, as reducing patient burden is of utmost importance in an already burdened cancer patient and caregiver population. According to Jenkinson, Fitzpatrick, Garrat, Peto, and Stewart-Brown (2001), lengthy instruments place a considerable amount of burden on patients. Also, according to these authors, lengthy instruments may compromise data if patients find their completion a burden. Instruments should be as simple and brief as possible while fulfilling the statistical requirements of validity and reliability (Jenkins et al, 2001). To reiterate, the Empathic Responding Scale appeared to have good face validity to capture the empathic behaviors of informal caregivers that were similarly captured in the Perspective-Taking Tools. However, the investigator's next step was to determine whether the Empathic Responding Scale might serve as a psychometrically valid, but abbreviated version of the Perspective-Taking Tool to capture the informal caregiver empathic behaviors as perceived by the patient.

In order to establish concurrent validity, the Pearson correlation coefficient  $r$  was calculated for the Empathic Responding Scale (DeLongis, 1990) in conjunction with the Perspective-Taking Tool PTCG (Long, 1990). The findings revealed that the Empathic Responding Scale (patient report of the caregiver's empathic behaviors) had a moderate, positive correlation (0.55) with the Perspective-Taking Tool PTCG (patient perception of the caregiver's empathic behaviors). In light of the moderate correlation, further analysis of the validity between the two scales is warranted in a larger sample of ovarian cancer

patients. However, the respective correlation between the Empathic Responding Scale and the Perspective-Taking Tool PTGC meets satisfactory criteria of 0.40 to 0.60 for establishing concurrent validity (Jacobson, 1997).

Although the investigator felt that participants understood the questions as worded on both empathic behavior scales, the participants were hesitant to rate their informal caregivers as not engaging in empathic behaviors. The investigator's overall impression was that participants were providing socially desirable responses to items on the Empathic Responding Scale and the Perspective-Taking Tool. The time to complete the Empathic Responding Scale was approximately 5 minutes and the Perspective-Taking Tools ranged from 10 to 15 minutes. This suggests that there would be a lower level of burden for cancer patients to complete items in response to caregiver empathic behaviors if one were to employ the Empathic Responding Scale instead of the Perspective-Taking Tool.

In summary, the investigator's analysis provides preliminary evidence to establish concurrent validity between the 10-item Empathic Responding Scale and the 20-item Perspective-Taking tool regarding patient perception on informal caregiver empathic behaviors in the caregiving relationship. Although ongoing validity testing is required, the evidence as presented here suggests that the use of the Empathic Responding Scale may be of feasible and valid use with ovarian cancer patients.

#### *Limitations*

There are some generalizability and methods limitations that caution the reader to carefully interpret the current study's findings. First, the investigator experienced a number of challenges in recruiting patient participants which resulted in the study's small

sample size of 13 ovarian cancer patients. Initially the investigator aimed to accrue a minimum sample size of 20 ovarian cancer patients over a three month period of data collection. However due to the low accrual rate, the data collection period was extended an additional three months, for a total of six months of data collection at two clinical sites. The resultant sample size of 13 patients limited the investigator's ability to conduct rigorous analyses to address the research questions. Nonetheless, a number of significant findings were discovered in relation to testing the relationships among patient physical symptoms, empathic behaviors, and patient psychological distress that lend tentative support for Lazarus and Folkman's (1984) theory.

Second, the study's patient sample was comprised mainly of participants of European descent who spoke English at home. This further reduces the generalizability of this study's findings to ovarian cancer patients of different ethnic backgrounds, religious affiliations, and whose first language may not be English.

Third, the investigator detected a consistent 'theme' that emerged over the course of interviewing the participants. This theme speaks to the hesitancy in participants to provide their partners with low ratings on the Empathic Behaviors Scale and the Perspective-Taking Tools. This finding may speak to the sensitive nature of evaluating the caregiver's empathic behaviors by patients. According to Polit and Beck (2004), this is consistent with a bias created by a phenomenon known as social desirability response set, in which participants have a tendency to misrepresent opinions in the direction of answers consistent with prevailing social norms. This is significant as the social desirability response set regarding the patient's responses to caregiver empathic behaviors may limit the veracity of their responses on the empathic behavior scales. This

has important clinical implications for clinicians and investigators who should consider actions that might prevent or reduce participant response bias. For example, clinicians or investigators might offer reassurance that the participant's responses will not be shared with the caregiver, or a reminder to the patient that he or she can reschedule the interview at a later date if privacy is an issue.

Fourth, all patient participants (n=13) were recruited from the Department of Psychosocial Oncology where they were receiving psychological support in support groups to help them cope with their illness. Therefore, this study sample may not have been representative of the entire ovarian cancer patient population of Manitoba where there are likely sub-groups of patients who are not receiving psychological support or who choose not to avail themselves of such support. Norton et al. (2005), reported that less than 60% of severely distressed patients receive any psychological intervention. However, the prevalence in psychological distress in this study sample (54%) is within the range of prevalence rates (23 to 67%) that were reported in other studies involving ovarian cancer and psychological distress. It is not known whether these results can be generalized to patients who are psychological distressed and not receiving psychological support.

#### *Implications for clinical practice*

The overall purpose of this study was to make more explicit the relationships among patient physical symptom experiences, empathic behaviors of caregivers as a form of social support, and the patient's status of psychological distress. Although generalizability of these findings may be limited, the present pilot study yielded valuable information regarding clinical implications in the care of ovarian cancer patients. In

particular, the current study's findings have implications for health care professionals to understand how to intervene in order to assist patients ameliorate the distress arising from physical and psychological symptoms.

First, to the best of this investigator's knowledge, there is no extant information regarding the administration of this study's instruments over the telephone. Prior to gaining access to CancerCare Manitoba, the investigator met with a social worker who expressed understandable concern regarding the utilization of the HADS over the telephone. This study provided valuable information about future utilization of the HADS and other instruments over the telephone. The investigator did not feel the study participations had experienced any difficulty in answering the questions in the study instruments, including the HADS. Furthermore, the investigator believed that the participants' responses were reliable in light of their ability to readily respond after the investigator provided them with a reasonable amount of time to think about and then respond to each item. Also, the investigator perceived no hesitancy in participants as they responded to the questions during the telephone interviews. Taking into consideration that the participants seemed to be at ease during the interviews (as evidenced by their willingness to ask questions and engage in an open dialogue regarding sensitive questions raised during the interview), the investigator concluded that the administration of the HADS and other study instruments over the telephone would be a feasible and possibly more convenient method of data collection for clinicians in the future.

Second, the results of this pilot study highlighted the clinical need to assess symptoms in ovarian cancer patients, as captured by a multidimensional symptom

assessment tool. This is significant as evidenced by the patient's ability to differentiate between the underlying symptoms dimensions of frequency, severity, and distress that can impact how the clinician chooses to intervene in responding to patient symptom experiences. Additionally, it is important to utilize a multidimensional instrument such as the MSAS because of the possibility that the frequency or severity of a symptom may not be associated with the level of distress from that symptom. For clinicians, taking into account the multidimensional experience of symptoms should enable their ability to target interventions with symptoms that are either highly distressing, experienced with greater frequency, or most severe to patients.

Third, this study found that patient depression was significantly related to patient reports of physical symptoms. This finding has an important implication for clinicians to be aware that patients' physical symptom experiences might be exacerbated by their psychological distress. This study has shown that physical symptoms and psychological distress are inter-related and thus clinicians should explore this possibility when dealing with patients who have unresolved or unexplained distressful physical symptoms.

Fourth, this study revealed that when patients perceived their caregivers had possessed a high level of understanding of their physical symptoms and emotions, patient also felt less psychologically distressed. This finding highlights the need to incorporate a clinical assessment of the level of caregiver knowledge of patient physical symptoms that can assist in ameliorating patient anxiety. Furthermore, clinicians can encourage empathic communication between the patient and the caregiver that has been shown in this study to be associated with patient perception of caregiver knowing his or her physical symptom status.

Fifth, this study established preliminary evidence toward the concurrent validity of the Empathic Responding Scale with the Perspective-Taking Tool when attempting to capture the patient's perception of the caregiver's empathic behaviors in the caregiving relationship. This finding is clinically significant as the use of a short, reliable instrument should help clinicians in their assessment of caregiving relationships, and thus reveal any issues or conflicts related to empathic communication that may impact patient care.

*Implications for future research*

The purpose of pilot work is not the same as that of a small-scale study where the purpose is to test research hypotheses (Polit & Beck, 2004). However, the purpose of this pilot study was to explore the feasibility of capturing ovarian cancer patient reports on physical symptom experiences, perceptions of their caregiver's empathic behaviors, and psychological distress with a series of instruments during a telephone interview. The investigator was also interested in exploring various recruitment strategies at a single-site, outpatient clinic setting and patient responses to sensitive issues in relation to their caregivers' empathic support in preparation for a larger study.

The investigator gleaned a better understanding about challenges that can be encountered in recruiting ovarian cancer patients at a single recruitment site. Future research should focus on obtaining access to a variety of sites that may aid in fostering optimal accrual rates, as well as addressing recruitment strategies that limit the demands placed on busy clinic staff to assist in the recruitment of patients in outpatient clinic settings. Further research should be pursued with a larger study sample to test the concurrent validity of the Empathic Responding Sale in capturing patient perceptions of caregiver empathic behaviors in the caregiving relationship. Ongoing research is

required to provide empirical evidence that supports theoretical relationships among patient physical symptom experiences, caregiver empathic behaviors, and patient psychological distress in the ovarian cancer patient population, as depicted in Lazarus and Folkman's (1984) theory of Stress, Appraisal, and Coping. In particular, investigators should also consider exploring the relationship between patient age and patient perception of caregiver empathic behaviors, patient anxiety, and possibly incorporate a measure of caregiver denial. Such information would be helpful in being able to develop interventions to enhance caregiver empathic behaviors or decrease patient anxiety in targeted groups of ovarian cancer patients of different ages.

#### *Summary*

The purpose of this pilot study was to investigate the linkage between physical symptom experience, empathic informal caregiver behavior, and psychological distress in ovarian cancer patients. Guided by Lazarus and Folkman's (1984) *Stress, Appraisal, and Coping* theory, it was hypothesized that appraisal of the cancer experience would be impacted by empathic informal caregiver behavior. In other words, if the patient perceived a lack of empathic informal caregiver behavior, patient physical symptom experience would increase and result in increased psychological distress. Despite the current study's small sample size, study findings revealed that significant associations existed among patient physical symptom experience, informal caregiver empathic behaviors, and patient psychological distress in the context of the caregiving relationship between ovarian cancer patients and their informal caregivers. Preliminary analyses suggested that clinicians and investigators might consider employing the Empathic

Responding Scale with ovarian cancer patients as a valid measure that captures patient perceptions of caregiver empathic behaviors, a dimension of patient social support.

Several implications for clinical practice and future research have been identified. Larger studies with patients diagnosed with ovarian cancer and patients with other cancer diagnoses would be helpful in terms of being able to generalize study findings and provide ongoing empirical support toward Lazarus and Folkman's (1984) theory.

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## Appendix A

### INVITATION AND PERMISSION TO RELEASE PATIENT NAMES

Sonia Bokhari, RN, a Master of Nursing student at the University of Manitoba is interested in conducting a study to learn about cancer patients' perceptions of their family caregivers' behavior towards them. She is also interested in learning whether this perception affects the psychological distress as well as physical symptoms those living with cancer might experience. This study has received ethical approval from the Education Nursing Research Ethics Board at the University of Manitoba.

Sonia would like to talk to you about the study to see if you might be interested in participating in it. Would you be willing to speak to her so that she can explain the study to you? You can let the clinical nurse or desk clerk know about your decision to speak to Sonia. Please indicate your decision on the 2<sup>nd</sup> page of this invitation and return it to your clinic nurse or desk clerk. You can speak to Sonia today, or leave your name and telephone number with the nurse or desk clerk so that Sonia can call you about the study. The information you leave on the 2<sup>nd</sup> page of this invitation should be strictly voluntary and you are not obligated to provide this information

If you agree to speak to Sonia today, or decide to leave your name and contact information on this letter of invitation it does not mean that you agree to participate in this study. Only when you have read, understood, and signed the attached letter of consent will Sonia enroll you as an individual who has agreed to participate in this study.

Should you decide to participate, all the information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you receive will not be affected by your decision to take part in or not take part in this study.

Thank you for considering this request. If you have any questions about the research study Sonia can be reached at

A study by Sonia Bokhari, R.N., B.N., Faculty of Graduate Studies,  
University of Manitoba

**This information is to be provided by you strictly on a voluntary basis.**

\_\_\_\_\_ Yes, I agree to speak to Sonia

---

NAME

---

TELEPHONE NUMBER

\_\_\_\_\_ No, I do not agree to speak to Sonia

**RETURN THIS PAGE IN THE ATTACHED  
ENVELOPE THAT IS SEALED TO YOUR  
CLINIC NURSE OR DESK CLERK**

## Appendix B

### Patient Consent Form

**Research Project Title:** Investigation of the Linkage between Empathic Informal Caregiver Behaviors, Physical Symptom Experiences and Psychological Distress in Ovarian Cancer Patients.

**Researcher:** Sonia Bokhari, RN, BN, University of Manitoba, Faculty of Nursing.

**Thesis Advisory Committee:** Dr. Michelle Lobchuk, University of Manitoba, Faculty of Nursing; Dr. Susan McClement, University of Manitoba Faculty of Nursing; Dr. Robert Lotocki, Gynecological Oncologist, CancerCare, Manitoba.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

#### **Nature and Purpose of the Study**

You are invited to take part in a study about ovarian cancer patient perceptions of their family caregivers' empathic behavior towards them, and whether this perception affects ovarian cancer patients' physical symptoms and psychological distress (anxiety and depression).

#### **What am I being asked to Consent to? What is the Nature of my Participation in the Study?**

If you consent to take part in the study, you are agreeing to answer the questions from 6 short questionnaires that the Researcher will ask you during telephone interview on a one-time basis.

The Researcher will first ask you some questions about your age, marital status, language, ethnicity, religion, occupation, and caregiving relationship, in order to understand and describe the overall characteristics of the ovarian cancer patients who take part in the study. She will ask you questions such as, "What is your age?", "What is your marital status?", and "What is your cultural or ethnic background?"

The Researcher will then administer the second questionnaire, which will ask you to rate statements about your feelings of anxiety and depression you may have been experiencing over the past week. For example, the Researcher will read a statement such as "I feel tense, or wound up", and ask you to choose the answer that best describes how you have been feeling over the past week from 4 choices, ranging from "Most of the Time", to "Not at all."

The third questionnaire will ask you about some of the physical symptoms that you might have been experiencing over the past week such as pain, nausea, and bloating.

The fourth questionnaire will ask you about your perceptions of your own behavior towards your family caregiver. The Researcher will ask you to rate statements such as "I realize what my caregiver means even when my caregiver has difficulty saying it" on a scale from 0 (Does not describe me very well) to 4 (Does describe me very well).

The fifth questionnaire will ask you about your perceptions of how your family caregiver behaves towards you. The Researcher will ask you to rate statements such as "My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from" on a scale from 0 (Does not describe my caregiver very well) to 4 (Does describe my caregiver very well).

The final questionnaire will ask you to rate some statements about how your family caregiver has tried to understand your illness experience, such as "My caregiver tries to understand my concerns" on a scale from 0 (Does not describe my caregiver very well) to 4 (Does describe my caregiver very well).

It is expected that answering the Researcher's questions will take about 35 minutes of your time. If you require assistance in understanding any of the questions, the Researcher will be pleased to assist you.

If you consent to take part in this study, you may also give the Researcher permission to access your chart at CancerCare Manitoba (formerly known as the Manitoba Treatment and Research Foundation) for medical information. If you do not want your chart accessed by the Researcher, but would still like to participate in the rest of the study that is fine. The medical information that will be sought from your chart will include: the type of cancer you have; the stage of your disease; the actual date of your diagnosis, the type of cancer treatment you may be receiving, and the types of cancer treatment you may have received in the past. The Researcher will access this information under the direction of the nurse who runs the clinic that you usually attend at CancerCare Manitoba. All information obtained from your medical record will be kept confidential, and will be

handled in accordance with the Personal Health Information Act (PHIA) guidelines. The information you do agree to provide will be collected for the purposes of the study, but your request to not access your chart will be respected.

Once the Researcher has finished collecting information from you, she will be willing to spend additional time with you to answer any questions that you may have about your responses to the questionnaires.

### **Handling of Information During & After the Study**

Any information that you provide to the Researcher will be kept confidential. The only exception would be if the Researcher discovered abuse in the course of the study, in which case she is legally bound to report this to the appropriate authorities. No personal identifying information will be recorded on any of the data collection forms used in this study. Your physician(s) will not know how you responded to this study's questions or that you participated in this study. The nurse who helps with accessing your chart will know that you are participating in this study, but will not know how you responded to this study's questions. To protect your identity, you will be assigned a code number that is known only to the Researcher, Sonia Bokhari, RN, BN. Only Sonia, the Researcher, will know the names of those who have agreed to take part in the study. Only the Researcher, her advisor, Dr. Michelle Lobchuk, and possibly a statistician will have access to the questionnaires that you completed. During and after the study, all consents and questionnaires will be locked up in a secure and private location, known only to Sonia. Study data will be kept for seven to ten years, after which it will be destroyed, and treated as confidential waste.

The results from this study may be published, and presented at scientific meetings. However, under no circumstances would your identity be revealed. Information will be reported in aggregate or group form as opposed to individual responses.

### **Benefits and Burdens Associated with Participating in the Study**

There are no immediate benefits to you for taking part in the study. However, the results of the study may be helpful to health professionals (like nurses and doctors) who want to know how to improve the care they give patients and their caregivers.

Although there are no known risks involved with participating in the study, it is recognized that the subject matter is of an emotional nature. The Researcher would be more than willing to talk with you about any feelings that may arise as a result of the questions. The Researcher will also provide you with information or resources at Cancer Care Manitoba, such as the Psychosocial Oncology Department, that you can contact to help you deal with issues or answer questions that may arise as a result of participating in this study.

### **Can I Get a Copy of the Results of the Study?**

A summary of the results of the study will be made available to you if you would like to receive them once the study is completed. To indicate your interest in receiving a summary of the study, please fill out the detachable form at the end of the consent.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. You may obtain information and clarification from the Principal Investigator (Researcher) of the study, Sonia Bokhari, RN, BN. Sonia can be reached by telephone at ( ) .

This research has been approved by the Education/Nursing Research Ethics Board (ENREB) of the University of Manitoba, and the Research Access Board of CancerCare Manitoba. If you have any concerns or complaints about this project, you may contact Sonia Bokhari at ( ), Sonia's thesis supervisor Dr. Michelle Lobchuk at (204) 474-7135, or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Prior to signing this consent form, please put a check mark in the box below that reflects your level of participation in this study.

I agree to participate in this study as outlined in this consent, and also give my permission for the Researcher to access my medical record at CancerCare Manitoba to collect information for the study as outlined in this consent.

I agree to participate in this study, however, I do not want my medical record at CancerCare Manitoba accessed by the Researcher to collect information for the study as outlined in this consent.

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Participant's Signature

Date

---

Researcher and/or Delegate's Signature

Date

**If you would like to receive a summary of the results of this study, please fill out the form below:**

Name of person to whom study results should be sent: \_\_\_\_\_

Mailing address  
\_\_\_\_\_  
\_\_\_\_\_

Postal Code: \_\_\_\_\_

## Appendix C

### Ovarian Cancer Patient Demographic Questionnaire

To begin our survey, I would like to ask you a few questions about your background. We ask these questions so that we can describe the overall characteristics of the group of people who took part in the survey.

1.	What language do you speak most of the time at home? (What is your main, or first language?)	1. English 2. French 3. Other (Specify) <hr style="width: 100%;"/>
2.	What is your cultural or ethnic background? For example, what part of the world do your ancestors come from? (How would you describe your ethnic or cultural heritage?)	Specify:
3.	What is your religion, if any?	1. No preference 2. Anglican 3. Baptist 4. Orthodox 5. Jehovah's Witness 6. Jewish 7. Lutheran 8. Mennonite 9. Pentecostal 10. Presbyterian 11. Catholic 12. United Church 13. Other (Specify) <hr style="width: 100%;"/>
4.	How far did you go in school?	1. Less than High school 2. High School Graduate 3. Partial College (at least one year) 4. College or University Graduate 5. Graduate/Professional Training

5.	What is your marital status? (Have you ever been married?)	<ol style="list-style-type: none"> <li>1. Married</li> <li>2. Common-law</li> <li>3. Never married</li> <li>4. Widowed</li> <li>5. Separated</li> <li>6. Divorced</li> </ol>
6.	What is your age?	_____
7.	What is your occupational status?	<ol style="list-style-type: none"> <li>1. Full-time</li> <li>2. Part-time</li> <li>3. Medical leave</li> <li>4. Unemployed</li> <li>5. Retired</li> </ol>
8.	What is your current (or previous) employment?	<ol style="list-style-type: none"> <li>1. Clerical</li> <li>2. Laborer</li> <li>3. Homemaker</li> <li>4. Professional</li> <li>5. Management</li> <li>6. Other (Specify)</li> </ol> _____
9.	What is your annual family income?	<ol style="list-style-type: none"> <li>1. Below \$10,000</li> <li>2. \$10,000-\$20,000</li> <li>3. \$21,000 -\$30,000</li> <li>4. \$31,000 -\$40,000</li> <li>5. \$41,000 - \$50,000</li> <li>6. \$51,000 - \$60,000</li> <li>7. \$61,000 - \$70,000</li> <li>8. Over \$71,000/year</li> <li>9. Refused</li> </ol>
10.	What type of ovarian cancer do you have?	<ol style="list-style-type: none"> <li>1. Epithelial ovarian cancer</li> <li>2. Sex Cord Stromal Ovarian Cancer</li> <li>3. Germ Cell ovarian Cancer</li> <li>4. Unknown</li> </ol>

11.	What stage is your ovarian cancer?	1. Stage I 2. Stage II 3. Stage III 4. Stage IV 5. Unknown
12.	What is the actual date of your diagnosis?	_____
13.	Are you receiving current treatment for ovarian cancer?	1. Yes 2. No
14.	If you are receiving current treatment for your ovarian cancer, what kind are you receiving? Check off all treatments that apply to you.	1. Chemotherapy 2. Radiotherapy 3. Surgery 4. Other (Specify) _____
15.	Did you receive treatment for ovarian cancer in the past?	1. Yes 2. No
16.	If you did receive treatment in the past, what kind of treatment did you receive? Check off all treatments that apply to you.	1. Chemotherapy 2. Radiotherapy 3. Surgery 4. Other _____
17.	Are you currently receiving nursing care in your home?	1. Yes 2. No
18.	If you are currently receiving nursing care in your home, how long have you been receiving nursing care? (in months)	_____

### Questions about the Caregiving Relationship

19.	How long has your carer been caring for you? (Months)	<ol style="list-style-type: none"> <li>1. 0 to 9</li> <li>2. 10 to 18</li> <li>3. 19 to 36</li> <li>4. More than 36</li> </ol>
20.	What is the extent to which your carer assists you in coping with your medical condition and symptoms?	<ol style="list-style-type: none"> <li>1. Never assists me</li> <li>2. Rarely</li> <li>3. Sometimes</li> <li>4. Frequently</li> <li>5. Always</li> </ol>
21.	What is the extent to which your carer assists you in coping with your emotions?	<ol style="list-style-type: none"> <li>5. Never assists me</li> <li>6. Rarely</li> <li>7. Sometimes</li> <li>8. Frequently</li> <li>5. Always</li> </ol>
22.	Do you and your carer talk openly about what your thoughts and feelings are in regard to your symptoms?	<ol style="list-style-type: none"> <li>1. Never</li> <li>2. Rarely</li> <li>3. Sometimes</li> <li>4. Frequently</li> <li>5. Usually</li> </ol>
23.	Do you and your carer talk openly about what your thoughts and feelings are in regard to your emotions?	<ol style="list-style-type: none"> <li>6. Never</li> <li>7. Rarely</li> <li>8. Sometimes</li> <li>9. Frequently</li> <li>10. Usually</li> </ol>
24.	How well do you think your carer knows 'how you think and feel' about your symptoms?	<ol style="list-style-type: none"> <li>7. Totally not at all</li> <li>8. Not very well</li> <li>9. Has some knowledge</li> <li>10. Adequate</li> <li>11. Very well</li> </ol>
25.	How well do you think your carer knows 'how you think and feel' about your emotions?	<ol style="list-style-type: none"> <li>12. Totally not at all</li> <li>13. Not very well</li> <li>14. Has some knowledge</li> <li>15. Adequate</li> <li>16. Very well</li> </ol>

26.	How much contact does your carer have with you?	<ol style="list-style-type: none"><li>1. Daily, my carers lives with me</li><li>2. Daily, but my carer doesn't live with me</li><li>3. More than weekly, I don't live with my carer</li><li>4. Weekly, I don't live with my carer</li><li>5. Less than weekly, I don't live with my carer</li></ol>
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## Appendix D

### Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Emotions play an important part in most illnesses. If the health care team is aware of these emotions they are better able to help you. This questionnaire is designed to help understand how you are feeling. Ignore the numbers on the left side of the page. Try not to take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought out response.

**A I feel tense or 'wound up':**

- 3 \_\_\_ Most of the time  
2 \_\_\_ A lot of the time  
1 \_\_\_ From time to time  
0 \_\_\_ Not at all

**D *I still enjoy the things I used to enjoy:***

- 0 \_\_\_ Definitely as much  
1 \_\_\_ Not quite as much  
2 \_\_\_ Only a little  
3 \_\_\_ Hardly at all

**A I get a sort of frightened feeling as if something awful is about to happen:**

- 3 \_\_\_ Very definitely and quite badly  
2 \_\_\_ Yes, but not too badly  
1 \_\_\_ A little, but it doesn't worry me  
0 \_\_\_ Not at all

(Continued on next page)

**D** *I can laugh and see the funny side of things:*

- 0 \_\_\_ As much as I always could  
1 \_\_\_ Not quite so much now  
2 \_\_\_ Definitely not so much now  
3 \_\_\_ Not at all

**A** **Worrying thoughts go through my mind:**

- 3 \_\_\_ A great deal of the time  
2 \_\_\_ A lot of the time  
1 \_\_\_ From time to time, but not too often  
0 \_\_\_ Only occasionally

**D** *I feel cheerful:*

- 3 \_\_\_ Not at all  
2 \_\_\_ Not often  
1 \_\_\_ Sometimes  
0 \_\_\_ Most of the time

**A** **I can sit at ease and feel relaxed:**

- 3 \_\_\_ Definitely  
2 \_\_\_ Usually  
1 \_\_\_ Sometimes  
0 \_\_\_ Most of the time

(Continued on next page)

**D** *I feel as if I am slowed down:*

- 3 \_\_\_ Nearly all the time  
2 \_\_\_ Very often  
1 \_\_\_ Sometimes  
0 \_\_\_ Not at all

**A** **I get a sort of frightened feeling like ‘butterflies’ in the stomach:**

- 0 \_\_\_ Not at all  
1 \_\_\_ Occasionally  
2 \_\_\_ Quite often  
3 \_\_\_ Very often

**D** *I have lost interest in my appearance:*

- 3 \_\_\_ Definitely  
2 \_\_\_ I don't take so much care as I should  
1 \_\_\_ I may not take quite as much care  
0 \_\_\_ I take just as much care as ever

**A** **I feel restless as if I have to be on the move:**

- 3 \_\_\_ Very much indeed  
2 \_\_\_ Quite a lot  
1 \_\_\_ Not very much  
0 \_\_\_ Not at all

(Continued on next page)

**D** *I look forward with enjoyment to things:*

- 0 \_\_\_ As much as I ever did  
 1 \_\_\_ Rather less than I used to  
 2 \_\_\_ Definitely less than I used to  
 3 \_\_\_ Hardly at all

**A** *I get sudden feelings of panic:*

- 3 \_\_\_ Very often indeed  
 2 \_\_\_ Quite often  
 1 \_\_\_ Not very often  
 0 \_\_\_ Not at all

**D** *I can enjoy a good book or radio or TV programme:*

- 0 \_\_\_ Often  
 1 \_\_\_ Sometimes  
 2 \_\_\_ Not often  
 3 \_\_\_ Very seldom

\*Please check to ensure that you have answered all questions. Thank-you.

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For researcher use only:

**D (8-10)** \_\_\_\_\_  
**A (8-10)** \_\_\_\_\_

### Appendix E

Patient No. \_\_\_\_\_

#### Empathic Responding Scale (Patient Perspective of Caregiver Empathic Behavior)

How well do the following statements describe your caregiver's behavior and actions with you on a scale of 1 to 4, where 0 does not describe your caregiver very well and 4 describes your caregiver very well. For each question circle the number that is the best description of your caregiver's actions towards you.

0	1	2	3	4	DOES DESCRIBE MY CAREGIVER VERY WELL		
DOES NOT DESCRIBE MY CAREGIVER VERY WELL							
1. My caregiver tries to understand my concerns.			0	1	2	3	4
2. My caregiver tries to understand how I felt.			0	1	2	3	4
3. My caregiver tries to experience what I was feeling.			0	1	2	3	4
4. My caregiver tries to imagine him/herself in my shoes.			0	1	2	3	4
5. My caregiver tries to see things from my point of view.			0	1	2	3	4
6. My caregiver tries to accept me as I am now.			0	1	2	3	4
7. My caregiver tries to help me by listening to me.			0	1	2	3	4
8. My caregiver tries to help me by doing something for me.			0	1	2	3	4
9. My caregiver tries to figure out What would make me feel better.			0	1	2	3	4
10. My caregiver tries to comfort me by telling me about their positive feelings for me.			0	1	2	3	4

## Appendix F

### Memorial Symptom Assessment Scale – Patient Self-Report

#### INSTRUCTIONS:

We have listed several symptoms on the next page. Read each question carefully. If you had any of these symptoms during this past week, please let us know how OFTEN you had them, how SEVERE they were usually, and how much they DISTRESSED OR BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE".

DURING THE PAST WEEK  Did you have any of the following symptoms?	D I D N O T  H A V E	IF YES,  How OFTEN Did you have it?				IF YES,  How SEVERE was it usually?				IF YES,  How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of Energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry Mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling Drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness/Tingling in the Hands/Feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling Bloating		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with Urination		1	2	3	4	1	2	3	4	0	1	2	3	4

DURING THE PAST WEEK  Did you have any of the following symptoms?	D I D N O T  H A V E	IF YES,  How OFTEN Did you have it?				IF YES,  How SEVERE was it usually?				IF YES,  How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of Breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with Sexual Interest/Activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty Swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of Appetite		1	2	3	4	1	2	3	4	0	1	2	3	4

DURING THE PAST WEEK  Did you have any of the following symptoms?	D I D N O T  H A V E	IF YES,  How SEVERE was it usually?				IF YES,  How much did it DISTRESS or BOTHER you?				
		Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much
Mouth Sores		1	2	3	4	0	1	2	3	4
Changes in the Way that Food Tastes		1	2	3	4	0	1	2	3	4
Weight Loss		1	2	3	4	0	1	2	3	4
Constipation		1	2	3	4	0	1	2	3	4
Hair Loss		1	2	3	4	0	1	2	3	4
I Don't Look Like Myself		1	2	3	4	0	1	2	3	4
Swelling of Arms/Legs		1	2	3	4	0	1	2	3	4
Changes in Skin		1	2	3	4	0	1	2	3	4
Other		1	2	3	4	0	1	2	3	4

Patient No. \_\_\_\_\_

**Appendix G****Perspective-Taking Tool- (Patient Self-Report)**

How well do the following questions describe your behavior and actions with the caregiver on a scale from 0 to 4, where 0 does not describe you very well, and 4 describes you very well. For each question circle the number that is the best description of your actions towards the patient.

0	1	2	3	4
DOES NOT DESCRIBE ME VERY WELL				DOES DESCRIBE ME VERY WELL

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1. When involved in an argument with my caregiver, I am the type of person who will consider and take into account my caregiver's point of view and compare that with my own. | 0 | 1 | 2 | 3 | 4 |
| 2. I am not good at understanding my caregiver's problems.  | 0 | 1 | 2 | 3 | 4 |
| 3. I not only listen to what my caregiver is saying but really understand and seem to know where my caregiver is coming from.   | 0 | 1 | 2 | 3 | 4 |
| 4. I do not seem to know how my caregiver feels.  | 0 | 1 | 2 | 3 | 4 |
| 5. I am able to accurately compare my caregiver's point of view with mine.  | 0 | 1 | 2 | 3 | 4 |

	0	1	2	3	4
	DOES NOT DESCRIBE ME VERY WELL				DOES DESCRIBE ME VERY WELL
6. I evaluate my caregiver's motivation for doing something before I make judgments about a situation.	0	1	2	3	4
7. I easily become impatient with my caregiver.	0	1	2	3	4
8. I am not able to put myself into my caregiver's shoes.	0	1	2	3	4
9. I nearly always know what my caregiver means.	0	1	2	3	4
10. I do not sense or realize what my caregiver is feeling.	0	1	2	3	4
11. I realize what my caregiver means even when my caregiver has difficulty saying it.	0	1	2	3	4
12. I do not usually understand the whole meaning of what my caregiver is saying to me.	0	1	2	3	4
13. I appreciate how the things my caregiver experiences, feel to him or her.	0	1	2	3	4
14. Before criticizing my caregiver, I try to imagine how my caregiver feels.	0	1	2	3	4

0 DOES NOT DESCRIBE ME VERY WELL	1	2	3	4	DOES DESCRIBE ME VERY WELL
15. If I think I am right about something, I don't waste much time listening to my caregiver's arguments.	0	1	2	3	4
16. I try to understand my caregiver better by imagining how things look from my caregiver's perspective.	0	1	2	3	4
17. I believe that there are two sides to every argument and I try to look at both sides.	0	1	2	3	4
18. I sometimes find it difficult to see things from my caregiver's perspective.	0	1	2	3	4
19. I try to look at my caregiver's perspective before making a decision.	0	1	2	3	4
20. When I am upset with my caregiver I try to put myself in my caregiver's shoes for a while.	0	1	2	3	4

Patient No. \_\_\_\_

**Appendix H****Perspective-Taking Tool (Perspective of Caregiver- Patient Perception)**

How well do the following questions describe your caregiver's behavior and actions with you on a scale from 0 to 4, where 0 does not describe your caregiver very well, and 4 describes your caregiver very well. For each question circle the number that is the best description of your caregiver's actions towards you.

0 DOES NOT DESCRIBE MY PARTNER VERY WELL	1	2	3	4	DOES DESCRIBE MY PARTNER VERY WELL
1. When involved in an argument with me, my caregiver is the type of person who will consider and take into account my point of view and compare that with his/her own.	0	1	2	3	4
2. My caregiver is not good at understanding my problems.	0	1	2	3	4
3. My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from.	0	1	2	3	4
4. My caregiver does not seem to know how I feel.	0	1	2	3	4
5. My caregiver is able to accurately compare his/her point of view with mine.	0	1	2	3	4

0 DOES NOT DESCRIBE MY PARTNER VERY WELL	1	2	3	4	DOES DESCRIBE MY PARTNER VERY WELL
6. My caregiver evaluates my motivation for doing something before he/she makes judgments about a situation.	0	1	2	3	4
7. My caregiver easily becomes impatient with me.	0	1	2	3	4
8. My caregiver is not able to put him/herself into my shoes.	0	1	2	3	4
9. My caregiver nearly always knows exactly what I mean.	0	1	2	3	4
10. My caregiver does not sense or realize what I am feeling.	0	1	2	3	4
11. My caregiver realizes what I mean even when I have difficulty saying it.	0	1	2	3	4
12. My caregiver does not usually understand the whole meaning of what I say to him/her.	0	1	2	3	4
13. My caregiver appreciates how the things I experience feel to me.	0	1	2	3	4
14. Before criticizing me, my caregiver tries to imagine how I feel.	0	1	2	3	4
15. If my caregiver thinks he/she is right about something he/she doesn't waste much time listening to my arguments.	0	1	2	3	4

0 DOES NOT DESCRIBE MY CAREGIVER VERY WELL	1	2	3	4	DOES DESCRIBE MY CAREGIVER VERY WELL
16. My caregiver tries to understand me better by imagining how things look from my perspective.	0	1	2	3	4
17. My caregiver believes that there are two sides to every argument and tries to look at both sides.	0	1	2	3	4
18. My caregiver sometimes finds it difficult to see things from my perspective.	0	1	2	3	4
19. My caregiver tries to look at my perspective before making a decision.	0	1	2	3	4
20. When my caregiver is upset with me he/she tries to put him/herself in my shoes for a while.	0	1	2	3	4