USING PHOTOVOICE TO ASSESS QUALITY OF LIFE IN INDIVIDUALS IMPACTED BY ADVANCED GYNECOLOGIC MALIGNANCIES

By

MEGAN LIPE ARMSTRONG

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2012
To Robert and Sandy Lipe
ACKNOWLEDGMENTS

Completing my dissertation would not have been possible without the immense expertise, love, and encouragement from all of my supporters. First and foremost, I’d like to thank my dissertation chair and mentor, Dr. Deidre B. Pereira for sharing her expert knowledge of the field of Psycho-Oncology and allowing me the freedom to conduct this project within her research lab. I am thankful for the confidence that Dr. Pereira had in me to pursue a dissertation project that is novel and challenging. Dr. Pereira has been my closest ally and mentor throughout graduate school, helping me develop both my clinical and research skills into what they are today. I have been truly inspired by her and given her mentorship, I will move on to the next step of my career with confidence, passion, and excitement. I cannot thank her enough for all of her guidance!

I would also like to acknowledge the contributions of the additional members of my dissertation committee including Dr. Ronald Rozensky, Dr. David Janicke, and Dr. Monika Ardelt. I am very thankful that they were willing to dedicate their time to provide the expertise and guidance necessary to complete this project. Their contributions have been invaluable and have shaped this project into a well-rounded, thoughtfully constructed study.

I am also thankful for and appreciate the funding received to facilitate this project by the College of Public Health and Health Professions at the University of Florida. This project was funded as a Public Health and Health Professions Model Demonstration Project and would not have been possible without this support.

I would like to thank my colleagues in the Psycho-Oncology laboratory for their assistance in recruiting participants and facilitating study groups. I appreciate the
contributions of Stacy Dodd, Ph.D., Tim Sannes, M.S., Seema Patidar, M.S., Shan Wong, B.S., and Rachel Postupak, M.S. I would like to give special recognition to Laura Telepak, M.S. for her extensive involvement in this project. Laura has played an integral role in the facilitation of study groups and has dedicated significant time to assist in the complex, and oftentimes lengthy analysis of the qualitative data. Without the help of my colleagues, the execution of this study would not have been possible.

I also extend gratitude to my family, particularly my parents, Sandra and Robert Lipe, for their never-ending support of my academic endeavors. I attribute much of my success to their unconditional love and their willingness to provide the support that has been necessary to facilitate achieving my goals. My husband, Brian Armstrong, has also played a large role in the completion of this project. He has always had an appreciation for the importance of this project to me and has risen to meet the demands that accompany the pursuit of my goals, including living apart for over two years. The extensive support from my parents and husband is something that I will always cherish.

Lastly, I owe an abundance of appreciation to the women and men living with ovarian cancer who have participated in this study. Their passion, openness, and willingness to give their time to this project has been truly inspiring. I feel incredibly blessed to have gotten the opportunity to know the participants in a way that many researchers are not afforded the chance to do. Learning their stories and their ability to cope with extraordinary circumstances is something that I will never forget. I am forever grateful for their involvement in this study.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>ACKNOWLEDGMENTS</th>
<th>................................................................................................................. 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>.................................................................................................................... 9</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>.................................................................................................................. 10</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>...................................................................................................................... 11</td>
</tr>
<tr>
<td>CHAPTER</td>
<td>....................................................................................................................... 13</td>
</tr>
</tbody>
</table>

## 1 INTRODUCTION

- Epidemiology of Gynecologic Cancer .............................................................. 13
- Treatment of Advanced Stage Gynecologic Cancers ......................................... 14
- Quality of Life in Women Impacted By Gynecologic Cancer ............................ 15
- Spouse-Caregiver Quality of Life ..................................................................... 16
- Mixed Methods in Quality of Life Research ...................................................... 19
- Photovoice ........................................................................................................ 20
- Use of Photovoice in the Cancer Population ..................................................... 21
- Photovoice as a Potential Psychosocial Intervention ......................................... 23
- Purpose of Study ............................................................................................... 24
- Primary Specific Aims ....................................................................................... 26
- Exploratory Aims .............................................................................................. 26

## 2 METHODS

- Design .................................................................................................................. 28
- Participants .......................................................................................................... 28
- Procedures ........................................................................................................... 29
  - Phase One ......................................................................................................... 30
    - Photo- Discussion Sessions ........................................................................... 31
    - Findings and Feedback Session ................................................................. 32
  - Phase Two ......................................................................................................... 32
- Pre- and Post-Photovoice Quantitative Psychosocial Assessment ...................... 33
- Analyses of Specific Aims ................................................................................. 35
  - Qualitative Data Preparation ........................................................................ 36
  - Interpretative Phenomenological Analysis .................................................... 36
  - Use of IPA in Psychosocial Cancer Research ................................................ 37
  - IPA Methodology ............................................................................................ 37
  - Measures to Reduce Interpreter Bias ............................................................ 38
  - Identifying Significant Data .......................................................................... 39

## 3 RESULTS ........................................................................................................... 41
Descriptive Results ........................................................................................................ 41
  Completion of Study Procedures ........................................................................ 43
  Photograph Assignments ..................................................................................... 45
Universal Themes .................................................................................................... 46
  Cognitive and Emotional Sequelae Overview ...................................................... 46
  Uncertainty .......................................................................................................... 47
  Frustration ........................................................................................................... 48
“Survival Techniques” ................................................................................................ 49
  Use of Humor ...................................................................................................... 49
  Spiritual/Religious Faith ...................................................................................... 50
  Maintaining Personal Identity and Control ........................................................... 51
  “Sadness Diversions” ................................................................................................ 52
  Making Preparations ............................................................................................ 53
Social Support ............................................................................................................ 54
  Specific Supporting Roles .................................................................................... 54
  Unique Spouse/Partner Caregiver Role ............................................................... 56
  Emotional Impact of Serving as Spouse/Partner Caregiver .................................... 58
  Patient Observation of Spouse/Partner Caregiver Struggle .................................... 59
Life Changes in the Context of Cancer ....................................................................... 60
  Changes in Relationships ..................................................................................... 60
  Increased Meaning ............................................................................................... 62
  Changes to Priorities/Values ................................................................................ 63
Discourse on Healthcare ............................................................................................ 64
  Ovarian Cancer-Specific Concerns ....................................................................... 66
Summary of Universal Themes .................................................................................. 67
Phase-Dependent Themes .......................................................................................... 68
  Burden of Support ............................................................................................... 68
  Advocacy ............................................................................................................. 70
  Learning to navigate the system ........................................................................... 71
  Discussion of Fear ............................................................................................... 72
  Frustration with Lack of Attention to Gynecologic Cancers .................................. 73
Summary of Phase-Dependent Themes .................................................................... 74
Participant Commentary on Photovoice ................................................................... 74
Exploratory Aims ....................................................................................................... 76
  Mood Disturbance ............................................................................................... 76
    Phase I ............................................................................................................... 77
    Phase II ............................................................................................................. 78
  Patient quality of life ............................................................................................ 78
  Spouse/partner caregiver quality of life ............................................................... 79
4 DISCUSSION ........................................................................................................... 81
Discussion of Results ............................................................................................... 81
Universal Themes: Cognitive and Emotional Sequelae ........................................... 81
  Uncertainty .......................................................................................................... 81
  Frustration ........................................................................................................... 83
Universal Themes: Personal “Survival Techniques” ................................................ 83
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-1</td>
<td>Participant demographic characteristics.</td>
<td>42</td>
</tr>
<tr>
<td>3-2</td>
<td>Study procedures completed by participants</td>
<td>45</td>
</tr>
<tr>
<td>3-3</td>
<td>Photograph assignments</td>
<td>45</td>
</tr>
<tr>
<td>3-4</td>
<td>Summary of universal themes</td>
<td>67</td>
</tr>
<tr>
<td>3-5</td>
<td>Summary of phase-dependent themes</td>
<td>74</td>
</tr>
<tr>
<td>3-6</td>
<td>Effect size differences in mood disturbance pre- and post- study</td>
<td>77</td>
</tr>
<tr>
<td>3-7</td>
<td>Effect size differences in patient quality of life pre- and post- study</td>
<td>79</td>
</tr>
<tr>
<td>3-8</td>
<td>Effect size differences in spouse/partner caregiver quality of life pre-</td>
<td>79</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-1</td>
<td>“Waiting for the other shoe to drop”</td>
<td>48</td>
</tr>
<tr>
<td>3-2</td>
<td>“Trapped Alive”</td>
<td>48</td>
</tr>
<tr>
<td>3-3</td>
<td>“My wife’s blings”</td>
<td>50</td>
</tr>
<tr>
<td>3-4</td>
<td>“My salvation”</td>
<td>51</td>
</tr>
<tr>
<td>3-5</td>
<td>“Daydreams: One dollar each”</td>
<td>53</td>
</tr>
<tr>
<td>3-6</td>
<td>“Back to life”</td>
<td>56</td>
</tr>
<tr>
<td>3-7</td>
<td>“Balancing Act”</td>
<td>58</td>
</tr>
<tr>
<td>3-8</td>
<td>“Sunsets on the Gulf”</td>
<td>62</td>
</tr>
<tr>
<td>3-9</td>
<td>“Little chunks of life”</td>
<td>63</td>
</tr>
<tr>
<td>3-10</td>
<td>“Earned not given”</td>
<td>65</td>
</tr>
<tr>
<td>3-11</td>
<td>“Comfort”</td>
<td>68</td>
</tr>
<tr>
<td>3-12</td>
<td>“The beginning”</td>
<td>71</td>
</tr>
<tr>
<td>3-13</td>
<td>“Knowledge bloom”</td>
<td>72</td>
</tr>
<tr>
<td>3-14</td>
<td>“We don’t know how much time we have”</td>
<td>73</td>
</tr>
</tbody>
</table>
The quality of life of individuals impacted by advanced gynecologic malignancies is poorly understood and has been understudied within the literature. Patients and spouse/partner caregivers living with advanced gynecologic cancer endure a multitude of stressors that could be potentially threatening to quality of life. Prior research that has been primarily investigator-driven has yielded inconsistent results with regard to their quality of life and its sequelae. To address gaps within the literature, the present study aimed to elucidate themes regarding quality of life in advanced gynecologic cancer patients and their spouse/partners using a method called Photovoice. Photovoice is a qualitative method of inquiry that is participant-driven and provides participants the opportunity to describe their personal experiences using photography in a group setting.

Nine women diagnosed with ovarian cancer and their spouse/partner caregivers participated in the present study, with four couples engaging in dyadic Photovoice groups and five couples in patient- or caregiver-only groups. The results replicate and
expand upon prior research, providing discussion of themes related to the ways in which patients and caregivers faced with ovarian cancer experience uncertainty, frustration, life changes, and difficulties within the healthcare system. Themes further illustrate the use of “survival techniques,” or coping strategies, used by individuals facing these challenges. Results also provide insight into ways in which women with ovarian cancer experience and navigate support from others that can be burdensome. Findings suggest that Photovoice is a method of inquiry that can be used to understand quality of life in individuals impacted by advanced gynecologic malignancies that elucidates themes above and beyond extant literature.

Analysis of the exploratory aims also provides preliminary evidence within a small sample that participation in Photovoice procedures is associated with improvements in mood and quality of life in spouse/partner caregivers regardless of group format and improvements in mood in women participating in patient-only groups. The findings of the present study extend current literature regarding the quality of life of individuals impacted by advanced gynecologic malignancies and provide preliminary evidence for future research to examine the potential of Photovoice to be used as an intervention tool.
Epidemiology of Gynecologic Cancer

Ovarian cancer is the eighth leading cancer among women and has the second lowest five-year survival rate among women, with only 44.7% of women surviving five years past diagnosis (American Cancer Society, 2007). Over 21,000 new cases of ovarian cancer were diagnosed in 2010 (American Cancer Society, 2009). Epithelial ovarian cancer is the most common malignant ovarian neoplasm, with forms including serous cystomas (i.e., a tumor or growth containing cysts), mucinous cystomas, and clear cell tumors. The median age at the time of diagnosis of epithelial ovarian cancer is 63 years and the incidence increases with age. Known risk factors include older age at first childbirth (i.e., 35 years or older) and prominent family history of ovarian cancer, including carriage of BRCA1 or BRCA2 mutations. Protective factors include younger age at pregnancy and first birth (i.e., prior to age 25), breastfeeding and use of oral contraceptives (National Comprehensive Cancer Network, 2010).

In addition to developing in the ovaries, primary serous, clear cell, and mucinous tumors may also occur in the fallopian tubes, peritoneum, or uterine corpus. As such, these variants are treated similar to and often result in similar outcomes (i.e., high risk of recurrence and treatment resistance) to advanced stage ovarian malignancies (National Comprehensive Cancer Network, 2007). The majority of the literature regarding psychosocial outcomes in the face of gynecologic malignancy focuses on women with ovarian cancer; however, due to the similarities across these advanced stage gynecologic malignancies, it is believed that the findings can be generalized to women living with variants occurring within other areas of the female genital tract.
Treatment of Advanced Stage Gynecologic Cancers

Ovarian cancer and its variants have often been referred to as “the silent killer” as it is usually diagnosed after the disease has significantly progressed (i.e., stages III and IV). Approximately 70% of women who are ultimately diagnosed with epithelial ovarian cancer present with advanced disease due to the subtle signs and symptoms of early stage ovarian cancer (e.g., bloating and urinary frequency). In fact, as few as approximately 19% of all ovarian cancers are found in the early stages.

Once diagnosed, women with advanced stage ovarian cancer face an intensive initial treatment course that typically involves surgical cytoreduction procedures or “tumor debulking” followed by six to eight cycles of chemotherapy. Cytoreduction surgeries can include radical pelvic dissection, bowel resection, splenectomy, lymph node resection, diaphragm stripping, partial hepatectomy, or a combination of these measures (National Comprehensive Cancer Network, 2007). Advanced stage ovarian cancer has the highest mortality rate among all gynecologic cancers (American Cancer Society, 2009) and less than 40% of women with ovarian cancer are fully cured (National Comprehensive Cancer Network, 2010). Indeed, approximately 75% of women diagnosed with epithelial ovarian cancer who achieve complete clinical remission following initial treatment will experience a relapse within 18 to 28 months (Mei et al., 2010). Consequently, with the use of more aggressive surgical procedures and improvements in supportive care in recent years, women with advanced ovarian cancer are living longer with the disease (National Cancer Institute, 2001). Thus, it has become increasingly important to address the quality of life of women who continue living with incurable disease that is coupled with intensive treatment.
Quality of Life in Women Impacted By Gynecologic Cancer

Quality of life is a multidimensional construct that encompasses physical, social, emotional, and functional well-being (Schipper, 1990). In the context of cancer, an individual’s baseline functioning in these areas is impacted by the disease and its associated treatment (Cella et al., 1993). Studies assessing quality of life and its correlates in women with advanced stage gynecologic cancers have resulted in mixed findings. The intensive adjuvant treatment regimens (i.e., chemotherapy) used to treat ovarian cancer often cause hair loss, weight changes, sexual dysfunction, mood changes, mucositis, fatigue, nausea/vomiting, and other impairing side effects. As a result, quantitative studies in women with ovarian cancer in various stages of disease and treatment often describe that they experience prolonged changes in body image, relationship disruption, fears of recurrence, and difficult thoughts related to end-of-life (Bodurka-Bevers et al., 2000 & Sun, Ramirez, and Bodurka, 2007). In addition, quantitative measurement of quality of life using the City of Hope Quality of Life Ovarian Cancer Tool, has been found to be significantly lower in women who have been diagnosed with stage III or IV ovarian cancer as compared to those diagnosed with stage I or II disease (Ferrell et al., 2005).

On the other hand, in a study by Houck, Avis, Gallant, Fuller, and Goodman (1999) in which an investigator-driven qualitative interview was used, a sample comprised of advanced stage ovarian cancer patients receiving palliative care reported an overall positive quality of life in which concern for family/friends and disease-related fear were balanced by a sense of hope and positive social support. These authors specifically reported that a limitation to their study sample was that participants varied greatly across treatment modalities and disease stage. Using quantitative methods
including modules of the commonly used Functional Assessment of Cancer Therapy measure, Kornblith and colleagues (2010) also reported that 90.4% of long-term survivors of advanced stage ovarian cancer without recurrence rated their overall quality of life as 5 or greater on a scale of 1 to 7 (very poor to excellent) and the majority (75%) reported experiencing positive life changes resulting from their cancer experience. Notably, however, over half of the women endorsed experiencing significant fear of recurrence and anxiety regarding their health, in addition to over 38% reporting body image concerns, sexual concerns, and future uncertainty. Thus, while women in this study appeared to report an overall good quality of life, many expressed several significant concerns and approximately one third felt they needed mental health treatment. The authors noted that with their focus on quantitative measurement of quality of life, they were unable to engage participants in in-depth discussions regarding their identified concerns.

**Spouse-Caregiver Quality of Life**

Spouse-caregivers of ovarian cancer patients are expected to provide intensive informal caregiving (e.g., transportation and attendance to medical appointments, offering emotional support, administering necessary prescriptions, wound care in post-operative periods, etc.). This may be highly stressful and difficult to manage, particularly in the context of undergoing role transitions in the household by assuming additional responsibilities as their wives experience pain and fatigue secondary to their disease and/or treatment.

Consequently, family caregivers of patients with advanced stage cancers often report that they feel underprepared for their transition to their new role as caregiver and have expressed a desire to receive education and assistance from healthcare providers.
in this domain (Grobe, Ilstrup, & Ahmann, 1981). A study consisting of primarily male spouse-caregivers of patients diagnosed with either lymphoma, breast, colorectal, or lung cancers measured unmet needs using a quantitative measure designed for the study called the Psychosocial Needs Inventory. Results from this study revealed that caregivers of women diagnosed with the aforementioned cancers often report a greater number of unmet psychosocial needs (e.g., sexuality concerns, feelings of guilt, support, and fatigue) as compared to the cancer patients for whom they are caring (Soothill et al., 2003). Regarding caregiver adjustment to a cancer diagnosis, mental health status appears to significantly decline from baseline (i.e., diagnosis) to one year following diagnosis and is correlated with patient physical health status in individuals who are caring for loved ones diagnosed with lung, breast, or colorectal cancers. In this sample in which the majority were male spouse-caregivers, those who care for patients experiencing a greater frequency of physical symptoms have been found to report subjective decreases in quantitatively-measured personal control, increased stress unrelated to cancer, and decreased emotional support (Ell, Nishimoto, Mantell, & Hamovitch, 1988). A recent study by Price and colleagues (2010) suggests that while women with invasive ovarian cancer may have higher rates of depression than that which is seen in community norms, their caregivers experience significantly higher rates of depression and anxiety than individuals in the community, as well as higher rates of anxiety than the ovarian cancer patients. These relationships were demonstrated using the Hospital Anxiety and Depression Scale, a self-report scale (Zigmond & Snaith, 1983). Male spouse-caregivers of women with advanced stage breast cancer have also endorsed higher levels of global distress, anxiety, and depression as well as lower
levels of support from family and friends than their patient counterparts on a quantitative measure, the Brief Symptom Inventory (Derogatis & Spencer, 1982). In both women with advanced stage breast cancer and their spouse-caregivers, social support appears to be a significant contributor to global psychological distress, anxiety, and depression (Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2009).

To summarize, it appears that there is no general consensus regarding the quality of life of women diagnosed with advanced stage gynecologic cancers, though this may be partially attributable to the heterogeneity of previous samples in terms of disease, treatment status, and recurrence status. Additionally, there are few studies that have specifically focused on spouse-caregivers of women with advanced stage gynecologic cancers. The existing evidence, however, reveals the following themes that may help explain quality of life in this group: (1) many advanced stage gynecologic cancer patients tend to report overall positive quality of life despite common concerns including recurrence, body image, and relationship disruption, (2) spouse-caregivers are significantly impacted by their wives' experiences, (3) both patients and spouse-caregivers have expressed having unmet needs, and (4) both patients and spouse-caregivers have discussed a desire for some sort of psychosocial intervention (e.g., mental health treatment and/or psycho-education). The majority of literature within this population has been quantitative in nature; thus, a qualitative component may be a critical method of broaching gaps in our current understanding of the unique quality of life experiences in this population. In fact, following an earlier review of quality of life literature in the ovarian cancer population, Le at al. (2003) suggest that a full assessment of quality of life issues in patients and caregivers can only be obtained
through a combination of both qualitative and quantitative methods. No published studies to date have implemented a mixed methods design or a Community Based Participatory Research approach in a clinical sample of women impacted by advanced stage gynecologic cancer and their spouse-caregivers.

**Mixed Methods in Quality of Life Research**

Ring, Gross, and McColl (2010) review the prior controversy in combining quantitative and qualitative research designs, stating that in the past, these methods were generally thought to be “radically incompatible.” However, they discuss that in order to address the improvement of scientific rigor, the qualitative researcher must employ a systematic approach to recruiting participants, implementing study protocol, and conducting analyses of the data. Fortunately, the use of mixed methods designs has increased as interdisciplinary studies have established the utility of incorporating both quantitative and qualitative methods to understand complex health conditions (Mendlinger & Cwikel, 2008). The mixed methods paradigm is thought to be based in pragmatic philosophy; thus the value of this approach is that it uses multiple viewpoints or perspectives to inform theory and practice (Johnson, Onwuegbuzie, & Turner, 2007). Further, Creswell (2009) describes that in mixed methods research, quantitative and qualitative components are used in combination to best understand a research problem. The chosen method of inquiry in research is dependent upon the research question. Qualitative methods are both exploratory and explanatory; thus, they are most appropriate when the research question is poorly understood, when prior evidence is limited, or in instances in which unique populations have not been the focus of any prior research. On the other hand, it is appropriate to choose quantitative methods when aiming to identify specific factors influencing an outcome or to assess the usefulness of
an intervention. A mixed methods design can then be used when the strengths of both qualitative and quantitative methods can best answer the research question (Creswell, 2009). Additionally, Glasgow and Emmons (2007) provide relevant suggestions for translating health care research into clinical practice as they corroborate that the strengths of qualitative and quantitative approaches in a mixed methods design can offset the limitations of each individual design (i.e., potential reliability issues and limited information, respectively).

**Photovoice**

A qualitative research method called Photovoice has been differentiated from other methods of inquiry including clinical interviews and focus groups (Wang & Burris, 1997). The unique characteristics of this method are related to the use of visual images that are generated by participants through photography to facilitate discussion regarding the needs and assets of a community. As discussed by Wang and Burris (1997), the use of cameras for this purpose is a novel, accessible, and appealing tool to most individuals and serves to prompt discussion regarding topics that may be difficult to broach and/or define.

It is thought that the Photovoice method allows individuals to relate the realities of their own lives to others and it can be considered a form of community-based participatory research (CBPR). According to the Agency for Healthcare Research and Quality (2009), CBPR is defined as a collaborative research approach that “creates bridges between scientists and communities through the use of shared knowledge and valuable experiences.” The Photovoice method began as a public health initiative to evaluate the needs and assets of communities using a form of communication that is accessible to any individual who is able to operate a camera (i.e., breaking assessment
barriers including language and level of education). The Photovoice method aims to achieve three primary goals: (a) to enable individuals to record and reflect their personal and community’s strengths and concerns through photography, (b) to provide knowledge and promote critical evaluation of important issues through discussion of the photographs, and (c) to reach influential decision-makers in the community through public showing and dissemination of the photographs (Wang & Burris, 1997). As a participant-based research method, Photovoice strives to empower individuals who are distressed, fearful, or disenfranchised to relate the most informative data regarding their experiences, needs, and strengths to researchers, healthcare providers, and the community (Wang & Burris, 1994). Given its unique advantages, the current study used Photovoice to achieve a comprehensive understanding of the most salient quality of life issues in individuals impacted by advanced gynecologic malignancies.

**Use of Photovoice in the Cancer Population**

To date, Photovoice has not been used in an advanced stage gynecologic cancer population; however, three published studies involving Photovoice have been conducted in other samples of individuals who have been impacted by cancer. A seminal study by Lopez, Eng, Randall-David, and Robinson (2005) provided valuable information regarding the quality of life concerns and assets of rural African American breast cancer survivors by promoting discussion through photography. Qualitative themes extracted through use of Photovoice procedures revealed that four primary quality of life concerns were driven by social forces including stigmatizing beliefs about cancer (e.g., that cancer is contagious), racial discrimination by healthcare providers, and cultural beliefs about African American women (e.g., the importance of the female caregiver role despite a cancer diagnosis). The quality of life concerns they reported
were seeking resources that are not complicated by stigmatization or discrimination, transition to the role of “cancer survivor,” feeling comfortable regarding the future, and serving as role models for other African American women. In addition to elucidating quality of life concerns, themes focusing on assets of this group of women emerged including relying on faith and spirituality and personal strategies for maintaining social standing in the community.

Photovoice methods have also been used to understand the unique experiences of Aboriginal women living with breast cancer (Poudrier & Mac-Lean, 2009). Through discussion of their photographs, themes were revealed that focused on the importance of awareness regarding Aboriginal identity, traditional beliefs, and spiritual practice. For example, an Aboriginal woman who practiced Cree spirituality provided a picture of her braided hair and discussed the spiritual significance of hair loss secondary to chemotherapy:

According to her father, the cutting of hair would signify the death of someone or mourning in the loss of a loved one. As such, she had never cut her hair. She said, ‘The only time that people cut their hair is when they lost loved ones, and that’s what I believe today. When I lost my hair, I cried. I cried. ‘Well now, maybe I’m gonna die I said to myself.’ Once she began to lose her hair and her braid was cut, her husband smudged the braid and prayed. (Poudrier & Mac-Lean, 2009, p. 311)

Lastly, in a more recent study, a group of young adult survivors of childhood cancer who were of Hispanic or Mexican ethnicity and their family members communicated their unique experiences using Photovoice (Yi & Zebrack, 2010). Interference of achieving developmental milestones, parenting concerns, lack of
discussion of cancer within the family, religious and spiritual coping, and the importance of culturally competent healthcare were important themes that were discussed by the survivors and their family members.

Regarding use of photography in women impacted by cancer, Frith and Harcourt (2007) stated, “Photo-elicitation can provide access to the private, everyday worlds of patients who are away from the hospital environment. This aspect allows for greater reflection on the larger context within which the patient experiences health, illness, and treatment.” As demonstrated in studies of three significantly diverse groups of individuals impacted by cancer, Photovoice appears to be an informative and unique tool for participants to communicate their experiences to influential others (Yi & Zebrack).

Photovoice as a Potential Psychosocial Intervention

The creative arts, a component inherent in Photovoice procedures (described in more detail in the Methods section), have been found to be therapeutic for individuals impacted by cancer. Specifically in patients with cancer, participation in interventions involving artistic expression has been associated with decreases in intrusive thoughts, increased sense of mastery (Reynolds & Prior, 2006), improved quality of life (Visser & Op’t Hoog, 2008), and decreases in negative emotional states (Puig, Lee, Goodwin, Sherrard, 2006). In 2004, Walsh, Martin, and Schmidt demonstrated that family caregivers who participated in a brief creative arts intervention reported statistically significant decreases in stress and anxiety. Therefore, prior evidence suggests that both cancer patients and family caregivers can experience benefits following involvement in interventions that center around artistic expression.
The Photovoice procedures not only involve visual communication, but also a group environment in which to discuss and process participant photographs with similar others. Thus, there are several similarities between this environment and a group psychotherapy setting. Yalom (1995) describes primary factors that elicit therapeutic change in group psychotherapy that are likely to emerge through the Photovoice process, with the most valuable being catharsis, self-understanding, interpersonal input (i.e., conferring with other group members), cohesiveness, and universality (i.e., normalization). Specifically with regard to cancer, there is also evidence that women recently diagnosed with ovarian cancer find support groups to be a positive resource (Ahlberg & Nordner, 2006). Therefore, in addition to its assessment utility, Photovoice may also serve as a psychosocial intervention for participants engaging in this creative arts group process, though this has not yet been measured in a chronic illness population.

**Purpose of Study**

The present study was designed to address several important gaps in the existing literature regarding the quality of life of women diagnosed with advanced stage gynecologic cancers and their spouse/partner caregivers. While women are living longer with advanced gynecologic cancer, there is a lack of consensus in the literature about how longer survival has impacted quality of life in this group. This may be in part due to the fact that previous studies have consisted of heterogeneous cancer samples and have used primarily quantitative, investigator-driven methods. It appears that previous findings are consistent with the multi-faceted nature of the quality of life construct, as patients who report having a “good” quality of life continue to endorse significant concerns regarding recurrence, sexuality, and body image (Bodurka-Bevers et al.,
In addition, spouse/partner caregivers of these women appear to have difficulty adjusting to the care-giving role and coping with their wives’ disease (Grobe, Ilstrup, & Ahmann, 1981; Ell, Nishimoto, Mantell, & Hamovitch, 1988; Price et al., 2010; Hassan-Ohayon, Goldzweig, Braun, & Galinsky, 2009). Of significance to both future research and clinical endeavors, both patients and caregivers within this population report having unmet psychosocial needs.

The study of quality of life among individuals impacted by advanced gynecologic malignancies may benefit from use of participant-driven and mixed models research for several reasons: (1) quality of life in cancer is a complex construct that will likely be best explained by a method involving pragmatic and diverse approaches (i.e., mixed methods), (2) the current quantitative literature has yielded incomplete and conflicting data regarding quality of life in this population, and (3) participant-driven and interactive measures of assessment (e.g., Photovoice) have yielded rich quality of life data in other cancer populations. Additionally, a critical aspect of a qualitative approach is that the act of establishing validity is put in the hands of the participants by allowing them to review and modify the themes that have emerged from the data (Creswell & Clark, 2007). This will be especially helpful in clarifying the complex relationship among this population in the existing literature (e.g., that patients describe having a “good quality of life” despite having major quality of life concerns).

In light of this, the present study focuses on implementing Photovoice methods with an ever-growing population of women diagnosed with advanced stage gynecologic cancers and their spouse/partner caregivers in order to understand their unique quality
of life experiences. Through the investigation of these phenomena using Photovoice, it is also important to understand the role of group format on the themes that emerge by completing the study in two phases. Additionally, brief quantitative measures will be used to assess the potential for Photovoice to emerge as a promising intervention technique worthy of future research in larger samples.

**Primary Specific Aims**

**Aim 1:** To examine quality of life impact of poor prognosis gynecologic cancers among women diagnosed with serous, mucinous, and clear cell gynecologic malignancies (e.g., ovarian epithelial, primary peritoneal, fallopian tube, and endometrial cancers) and their spouse/partner caregivers.

**Hypothesis 1:** Using Photovoice, quality of life themes will emerge among women with gynecologic malignancies and their spouse/partner caregivers that have not been previously identified in prior published qualitative or quantitative research.

**Sub-Aim 1:** To compare and contrast emergent quality of life themes elucidated in Phase I (dyadic Photovoice groups) versus Phase II (patient- or caregiver-only Photovoice groups).

**Sub-Hypothesis 1:** Quality of life themes will emerge that are unique to each group condition.

**Exploratory Aims**

**Aim 2:** To estimate effect size differences in quality of life indices from pre- to post-Photovoice participation in women with gynecologic malignancies.

**Hypothesis 2:** At least a medium effect size difference (i.e., improvement) will emerge on mood and cancer-related quality of life from pre- to post-Photovoice participation.
**Aim 3:** To estimate effect size differences in quality of life indices from pre- to post-Photovoice participation in spouse-caregivers of women with gynecologic malignancies.

**Hypothesis 3:** At least a medium effect size difference (i.e., improvement) will emerge on mood and caregiver-related quality of life from pre- to post-Photovoice participation.
CHAPTER 2
METHODS

Design

The present study is a prospective, mixed methods design. The sample consists of nine women with advanced gynecologic cancer and nine spouse/partner caregivers. Participants were recruited from the UF&Shands Gynecologic Oncology Clinic in Gainesville, Florida. Participants were involved in a series of sessions focusing on the training, implementation, and discussion of Photovoice procedures and completed quantitative psychosocial questionnaires pre- and post-study participation. This study has been approved by the Institutional Review Board (IRB) of the University of Florida (Project number 645-2005) and was conducted according to IRB rules and regulations. This project was initiated as a collaboration among investigators in the departments of Clinical and Health Psychology (Deidre B. Pereira, Ph.D.), Medicine (Michelle M. Bishop, Ph.D., and Behavioral Science and Community Health (Ellen D.S. Lopez, Ph.D., M.P.H.). It was funded by the College of Public Health and Health Professions as a Public Health and Health Professions Model Demonstration Project.

Participants

The patient participants in this study included women diagnosed with primary or recurrent ovarian cancer, peritoneal cancer, fallopian tube cancer, papillary serous endometrial cancer, mucinous endometrial cancer, or clear cell endometrial cancer in the past five years. Patient exclusion criteria included: (a) physician estimated survival of fewer than six months, (b) Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) score < 20, (c) current DSM-IV-TR (American Psychiatric Association, 2000) diagnosis of a psychiatric condition that would interfere with the ability to
participate in Photovoice procedures, (d) current suicidal ideation/intent on the Beck Depression Inventory II (Beck, Steer, & Brown, 1996), and (e) spouse/partner caregiver unwilling to participate. Caregiver participants included the spouse/partner caregivers of patient participants. Exclusion criteria for caregiver participants included (a) through (d) listed above.

Procedures

Recruitment for the present study was accomplished using two methods. Participants were primarily recruited from the UF&Shands Gynecologic Oncology Clinic in Gainesville, Florida (Attending Physician, Dr. Linda Morgan). Potentially eligible participants were identified at their regularly scheduled clinic visits by research personnel. The attending physician, medical resident, or nurse notified potentially eligible patient participants of the opportunity to participate in this research project. A trained member of the research team met with eligible patients who expressed interest in the study in order to discuss study details and answer any questions. Patients willing to participate were asked to review and sign an IRB-approved informed consent form during their clinic visit. If the spouse/partner caregiver was available at the clinic visit, he provided informed consent simultaneously with the patient participant. Spouse/partner caregivers who were not available at this clinic visit were contacted by telephone to provide verbal consent and then provided written informed consent at the initial Photovoice training session prior to completing any study procedures. In the event that the patient’s medical chart indicated any evidence of impaired cognitive functioning or a history of suicidal ideation/intent, the aforementioned screening measures (i.e., MMSE and BDI-II) were administered to confirm the patient’s eligibility status prior to initiation of study procedures.
The study was also advertised using a standardized advertisement that was approved by the Institutional Review Board. The advertisement provided a brief description of the study, eligibility criteria, and study coordinator contact information. The Ovarian Cancer Alliance of Florida posted this advertisement in their monthly newsletter. The advertisement was also used in other similar community settings involved in gynecologic cancer awareness, advocacy and/or support. Participants who learned of the study in this manner and contacted the study coordinator were provided the opportunity to gain additional information prior to enrolling in the study. Participants provided verbal consent by telephone and then provided written informed consent at the initial Photovoice training session prior to completing any study procedures.

**Phase One**

Following informed consent, patient and spouse/partner caregiver participants within each cohort completed all Photovoice sessions together (i.e., dyadic groups). All Photovoice sessions were conducted by trained members of the research team, including graduate students and the Principal Investigator. All facilitators were trained by the Principal Investigator or an advanced graduate student who had completed training with the Principal Investigator and was approved as a trainer. Training involved in-depth protocol review, listening to audiotapes of prior Photovoice sessions, and experiential learning (i.e., attendance at one or more Photovoice sessions as an observer). While facilitators varied by cohort, the same research team member(s) conducted all sessions within cohorts to maintain continuity. Initial study procedures involved a Photovoice training session, lasting approximately one hour, in which participants completed baseline psychosocial questionnaires (see below) and were provided with detailed instructions regarding the study by a trained member of the research team. Specifically,
project aims and study protocol were reviewed and participant questions were elicited. The research team member discussed ethical and safety implications for camera usage and instructed participants regarding use of the “Photo Release (Consent/Assent) Form” in the event that they decided to photograph individuals in the community. Digital cameras were distributed to all study participants, and basic camera usage was reviewed. Participants were allowed the opportunity to elect using personal cameras if they desired. Lastly, the participants and research team member discussed and assigned the first photograph assignment. Given the participant-driven nature of this study, the research team member asked participants to consider the aspect of their cancer experience that they would most like to explore through photography. The sole responsibility for choosing the assignment rested on the participants themselves. Once a consensus about a topic was reached, the first Photo-Discussion Session was scheduled.

Photo-Discussion Sessions

Photo-Discussion Sessions I and II were audio-recorded with participant permission. These sessions ranged from approximately one to one and a half hours in length. After aims of the study and feedback regarding the assignment were discussed, participants reviewed their digital photographs and chose the ones they wished to share with the group. The chosen digital photographs were uploaded onto a laptop computer and the participants explained why they took their photographs and how it related to the photo-assignment. The research team member also conducted a Show and Tell Activity, a six step inductive questioning technique used to elicit personal and societal level discussion regarding the photographs. The six steps were as follows: “What do we see in this picture?”, “What is happening?”, “How does this relate to our lives?”, “Why do these
issues exist?” “How can we be empowered by our new social understanding?” and “What do we do to address these issues?” Following discussion of these photographs, an assignment for the second Photo-Discussion Session was mutually agreed upon by the participants and the research staff.

Findings and Feedback Session

The Findings and Feedback Session was the final Photovoice group meeting and was typically one hour in length. In this session, patient and caregiver participants were asked to discuss and assess the findings related to the themes that emerged from the qualitative analysis of the audio-taped transcripts from the prior two Photo-Discussion Sessions. Participants were asked to express the extent to which the presented findings (i.e., quality of life themes) seemed valid in depicting what they wanted others to understand about their cancer experiences. In the event that findings were deemed “inaccurate” by participants, the investigator and participants discussed the necessary modifications. Study participants were also given the opportunity to discuss their thoughts/feelings regarding Photovoice procedures. Specifically, participants were asked to discuss their opinions related to the use of photography to express their unique experiences with advanced stage gynecologic cancer, the process of taking and discussing their personal photographs, and any modifications to the study that they recommended. These focused discussions provided ways in which future studies and programs could potentially be improved. Following the discussion, participants completed post-study psychosocial questionnaires.

Phase Two

Phase Two was designed such that patient participants and spouse/partner caregivers were given the opportunity to engage in private discussions among like
individuals. Recruitment and psychosocial assessment procedures for Phase One and Phase Two participants were identical. Couples within each cohort enrolled in Phase Two of the study participated in the Photovoice Training Session, Photo-Discussion Sessions, and Findings and Feedback Sessions separately. In other words, each cohort in Phase Two consisted of a patient group and a spouse/partner caregiver group. Photovoice sessions were conducted concurrently; however, the couples did not participate in these sessions together. As a result, the two groups (Patient group and Spouse/Partner Caregiver group) designed and discussed separate photograph assignments.

**Pre- and Post-Photovoice Quantitative Psychosocial Assessment**

**Screening Assessment:** The Beck Depression Inventory: Second Edition (BDI-II) is a widely used 21 item self-report questionnaire that measures depressive symptomatology in adults (Beck, Steer, & Brown, 1996). Participants who endorsed current suicidal ideation on the item measuring thoughts of suicide were excluded from the study and triaged appropriately. In addition, participants that were suspected of having cognitive impairment completed the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975). The MMSE is a brief, 30 item, clinician-administered test that measures attention, concentration, and orientation. Participants who received a score of 24 or lower, suggesting cognitive impairment, were excluded from study participation.

**The MacArthur Sociodemographic Questionnaire (MSQ):** The MSQ (Adler et al., 2000) was used to assess basic patient and caregiver demographic information including perceived social status, level of education, income, and employment status.
Additionally, patient participants completed a brief health assessment survey with questions specific to their cancer diagnosis and treatment.

**Profile of Mood States (POMS):** Patient and spouse/partner caregiver participants completed a brief version of the Profile of Mood States (Mini-POMS) questionnaire (McNair, Lorr, & Droppleman, 1981) immediately prior to and following each Photovoice meeting. The Mini-POMS is a seven item Likert scale used to assess a range of mood states including those related to anxiety, depression, anger, and fatigue. It also provides a score for total mood disturbance. A total mood disturbance score was achieved by calculating the sum of variables measuring anxiety, depression, anger, confusion, and fatigue and subtracting the variable signifying the extent to which the participant felt energetic. This instrument has successfully been used to measure intervention benefits in a chronically ill and vulnerable population (Cruess, Antoni, Kumar, & Schneiderman, 2000).

**Functional Assessment of Cancer Therapy – Ovarian (FACT-O):** The FACT-O is a 38-item instrument that measures adjustment to living with ovarian cancer and well-being (Basen-Engquist et. al, 2001). This measure asks participants to rate the extent to which statements regarding well-being are true to their experiences. Examples include, “I have a lack of energy,” “I am satisfied with family communication about my illness,” “I worry about dying,” and “I am able to work.” In addition to yielding a total well-being score, subscales include physical well-being (PWB), functional well-being (FWB), emotional well-being (EWB), family/social well-being (SWB), and ovarian cancer-specific well-being (OCS). Evidence of FACT-O reliability has been demonstrated as the total score, FWB, PWB, and EWB scales showed very good
reliability, with Cronbach’s alphas and test-retest correlations between greater than
0.80. Test-retest correlations and Cronbach’s alpha for subscales SWB and OCS were
between 0.70 and 0.80, demonstrating adequate reliability. Satisfactory construct
validity and sensitivity to change have also been established. Patient participants will
complete the FACT-O during the Photovoice Training Session (prior to initiating any
Photovoice procedures) and immediately following the Findings/Feedback Session.

**Caregiver Quality of Life Index – Cancer (CQOLC):** Spouse/partner caregiver
participants were administered the CQOLC during the Photovoice Training Session and
immediately following the Findings and Feedback Session. The CQOLC is a 35-item
measure that specifically assesses the impact of caring for a loved one with cancer on
caregiver quality of life (Weitzner, Jacobsen, Wagner, & Cox, 1999). Participants were
asked to rate the extent to which statements related to caregiving represent their
experiences. Examples include, “It bothers me that my daily routine is altered,” “My
sleep is less restful,” and “I am satisfied with my sex life.” Cronbach’s alpha has been
estimated to be 0.91 and test-retest reliability is 0.95. Additionally, validity has been
demonstrated as the CQOLC has been correlated moderately with scales measuring
aspects of quality of life including depression, anxiety, and physical health status that
have been individually measured in previous studies assessing quality of life in
caregivers of cancer patients.

**Analyses of Specific Aims**

**Aim 1:** To examine quality of life impact of poor prognosis gynecologic cancers
among women diagnosed with serous, mucinous, and clear cell gynecologic
malignancies (e.g., ovarian epithelial, primary peritoneal, fallopian tube, and endometrial
cancers) and their spouse/partner caregivers.
Sub-Aim 1: To compare and contrast emergent quality of life themes elucidated in Phase I (dyadic Photovoice groups) versus Phase II (patient- or caregiver-only Photovoice groups).

Qualitative Data Preparation

The Photo-Discussion Sessions and Findings and Feedback Session for each cohort were audio-recorded with participant permission. Once the sessions were completed, research staff transcribed the content of these sessions verbatim. For organizational and referential purposes, transcripts were formatted such that the page numbers and line numbers were displayed.

Interpretative Phenomenological Analysis

Qualitative data were analyzed using a method called interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003). IPA is a methodology in which the researcher’s primary purpose is to understand, as best they can from the participants’ point of view, how they are making sense of the world around them. According to Smith and Osborn, “IPA and mainstream psychology converge in being interested in examining how people think about what is happening to them but diverge in deciding how this thinking can best be studied.” In other words, while mainstream psychology tends to focus on the quantitative representation of a participant’s experiences, in IPA the primary sources of data are the meanings that the participant attaches to his/her personal experiences. Therefore, for the purposes of the present study, IPA was used to understand, from their perspective, the quality of life of patients and spouse/partner caregivers living with advanced gynecologic cancer. It is also recommended that IPA be used in small, homogenous samples, making it appropriate for use in this study.
Use of IPA in Psychosocial Cancer Research

IPA has been effectively used in prior cancer research to organize and interpret qualitative outcomes. In 2011, Villhauer used IPA to understand interviews in which women with metastatic breast cancer discussed their experiences regarding involvement in support groups that were tailored towards women with advanced disease (i.e., stage-specific) versus mixed-stage groups (i.e., groups also consisting of women with earlier, less threatening forms of the disease). Using IPA, the author found that not only did women with metastatic breast cancer prefer stage-specific groups, but that they also experienced feelings of helplessness and a loss of voice in mixed groups because they felt that participants in mixed groups were not comfortable discussing the realities of advanced stage cancer. Additionally, IPA has been used in one prior published study related to ovarian cancer. Buckmaster and Gallagher (2010) analyzed semi-structured interview transcripts using IPA to gain an understanding of female participants’ thoughts regarding genetic testing for ovarian and breast cancer in non-traditional settings. The authors found that women were skeptical of and potentially distressed by engaging in genetic testing outside of a medical setting, providing valuable data to inform future practice.

IPA Methodology

In the present study, in order to maintain scientific rigor, specific and consistent procedures were used to interpret the qualitative data using IPA. Prior to providing any commentary, trained interpreters first read each of the transcripts two times in order to become immersed in the data. For the purpose of conducting the analyses, documents containing the transcribed Photovoice sessions were formatted to have wide margins. Upon the third reading, the interpreter then used the left margin to record content from
the session that was significant (i.e., any content related to the participants’ experience with cancer). This process was much like a “play by play” commentary from a sports announcer as it forced the interpreter to condense the content of the session into highlights. Once this was completed for the entirety of one session, the interpreter returned to the beginning of the transcript where the notations on the left margin were re-read in order to extract over-arching themes that were then recorded on the right margin. After the completion of this two step process for that transcript, the emergent themes were then organized in a separate document by conceptual category in order to connect the themes. These conceptual categories were designed and used as organizational tools as the interpretation progressed. In other words, the themes found in any given transcript dictated the conceptual categories that were used to make sense of them. For example, as a participant described or displayed any emotional reaction to cancer, the category “Emotional Reaction to Cancer” was formed and any instances of these phenomena were recorded under this heading. Page and line numbers for each of these instances were also recorded to provide quick references within the transcripts.

Once this interpretive process was completed for all of the transcripts, a separate and final table was constructed to list and categorize the superordinate themes across transcripts. Given our decision to compare emergent themes across Phase I and Phase II participants, two final tables were arranged. The two final tables were compared and contrasted, forming the narrative to illustrate the study results.

**Measures to Reduce Interpreter Bias**

The process of IPA is subject to interpreter bias given that the interpreter must rely on his/her clinical judgment to help make sense of what the participants are saying in the transcripts. With this in mind, extensive measures were taken to reduce the
potential for interpretive bias. First, each of the transcripts was separately coded using the aforementioned method by two trained members of the research team, including the author. Upon completion of these coding procedures, the findings were reviewed together to determine the extent to which the interpretations were comparable. During instances in which findings were divergent among interpreters, time was spent to reread the passage together and reach a consensus regarding the most accurate interpretation in order to achieve inter-rater agreement. Upon completion, the findings (i.e., each interpreter’s hand-written notes and the summary sheet detailing themes) were sent to the Principal Investigator, Dr. Deidre B. Pereira for review. Dr. Pereira then evaluated these materials and made adjustments as necessary, making this the final component of the review process.

**Identifying Significant Data**

Given the large amount of data gathered among these sessions, it was important to implement a distinct method for defining “significance” in order to focus the way in which the results were presented. Smith and Osborn (2003) described, “The themes are not selected purely on the basis of their prevalence within the data. Other factors, including the richness of the particular passages that highlight the themes and how the theme helps illuminate other aspects of the account, are also taken into account.” These factors, in addition to the extent to which data were informative above and beyond current literature, were considered when identifying significant themes.

**Analyses of Exploratory Aims**

**Exploratory Aims 2 and 3:** To estimate effect size differences in quality of life indices from pre- to post-Photovoice participation in women with gynecologic malignancies (Aim 2) and their spouse/partner caregivers (Aim 3).
Given our small sample size, albeit one that is common within the Photovoice literature, there is not sufficient statistical power to examine whether statistically significant differences exist in quality of life indices from pre- to post-Photovoice participation. Therefore, only effect sizes were calculated. Using Cohen’s d to examine the difference between means pre- to post-Photovoice participation, effect size differences were estimated in this population using three empirically validated instruments (Mini-POMS, FACT-O, and CQOLC). The FACT-O and CQOLC were only administered at pre- and post-study participation time points; however, the Mini-POMS was completed at each study visit pre- and post-Photovoice session. For the purpose of measuring changes in mood following completion of all study procedures, only the Mini-POMS values obtained at the pre- and post- study time points were used in the analyses. According to Cohen (1988), an effect size of 0.10 to 0.29 constitutes a small effect size, 0.30 is considered medium, and 0.50 is a large effect size. These widely accepted standards were used to evaluate the magnitude of the differences in quality of life from pre- to post-Photovoice participation among both patients and their spouse/partner caregivers. A meta-analysis of studies involving a variety of psychosocial interventions (e.g., psycho-education, support groups, psychotherapy) targeting quality of life in cancer patients yielded an average effect size of $d = 0.65$ (Rehse & Pukrop, 2003). Therefore, it was anticipated that at least medium effect size differences would emerge in our sample pre- to post-Photovoice participation.
CHAPTER 3
RESULTS

Descriptive Results

Approximately 138 patients were screened as eligible for this study between 2007 and 2011. Approximately 34% of eligible patients declined due to the length of distance they lived from the treatment center. Other reasons for declining occurred less frequently and included desire to “move on” from the cancer experience, scheduling conflicts, unwilling spouse/partner caregiver, and disliking photography. Of the eligible patients, 36 women signed informed consent and were enrolled in the study. Approximately 14 patient participants were lost to follow-up and 12 patient participants withdrew from the study due to either decreased interest, time constraints, distance, or most commonly, declining health. As it was more common for spouse/partner caregivers to enroll in the study at the Photovoice Training Session, fewer (i.e., 13) spouse/partner caregivers signed informed consent. Two spouse/partner caregiver participants were lost to follow-up and two were withdrawn from the study due to ineligibility following patient death.

Table 3-1 summarizes the demographic characteristics of participants who completed study procedures. Phase I consisted of three cohorts, with a total of four couples. The average age of patient participants \((N = 4)\) was 57.75 years \((SD = 3.86)\). Spouse/partner caregivers \((N= 4)\) were 70.75 years of age \((SD = 4.92)\). All couples in Phase I were married and Caucasian. Three patients in Phase I were diagnosed with Stage III ovarian cancer, and one was diagnosed with Stage IV. The amount of time between initial diagnosis and enrollment in the study was an average of 3.24 years \((SD = 1.13)\), with time ranging from 1.56 to 3.98 years. All of the women were treated with a
combination of surgical procedures (e.g., TAH-BSO, hysterectomy, omentectomy, and colon resection) and chemotherapy. Seventy-five percent of women had additional chronic health problems including arthritis, asthma, panic attacks, peripheral neuropathy, and severe diverticulitis.

Phase II consisted of two cohorts, totaling five couples. On average, participants in Phase II were younger as the mean ages for patients ($N = 5$) and spouse/partner caregivers ($N = 5$) were 64.80 ($SD = 13.44$) and 67.60 ($SD = 19.34$), respectively. All participants were Caucasian. Four couples were married and one couple was unmarried, but in a committed relationship. One participant was diagnosed with Stage I ovarian cancer, three women were diagnosed with Stage III, and one with Stage IV. Regarding duration of time between initial diagnosis and enrollment in the study, this ranged from 1.07 to 15.77 years; however, all patients had a diagnosis of either primary or recurrent ovarian cancer within five years of study enrollment. For women in Phase II, the median duration of time between study enrollment and initial diagnosis was 2.64 years. Treatment modalities for all of the women included surgery (e.g., TAH-BSO, omentectomy, appendectomy, resection of colon, bladder, and urinary tract) and chemotherapy. Only 20% reported having additional health problems and these included diabetes and hemochromatosis.

Table 3-1. Participant demographic characteristics

<table>
<thead>
<tr>
<th>Patients ($N=9$)</th>
<th>Phase I</th>
<th>Phase II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Yrs), Mean (SD)</td>
<td>57.75 (3.86)</td>
<td>64.80 (13.44)</td>
</tr>
<tr>
<td>Highest Degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School or GED</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Associate degree</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Bachelor's degree</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Master's degree</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Professional degree</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 3-1. Continued

<table>
<thead>
<tr>
<th>Patients (N=9)</th>
<th>Phase I</th>
<th>Phase II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16,000 – 24,999</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>25,000 – 34,999</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>35,000 – 49,999</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>50,000 – 74,999</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>75,000 – 99,999</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>100,000 or greater</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Hispanic/Latino</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

| Caregivers (N=9) | | |
| Age (Yrs), Mean (SD) | 70.75 (4.92) | 67.60 (19.34) |
| Highest Degree (%) | | |
| High School or GED | 1 | 2 |
| Bachelor's degree | 1 | 0 |
| Master's degree | 1 | 0 |
| Doctoral degree | 1 | 1 |
| Professional degree | 0 | 2 |
| Household Income | | |
| 25,000 – 34,999 | 1 | 0 |
| 35,000 – 49,999 | 0 | 1 |
| 50,000 – 74,999 | 0 | 2 |
| 75,000 – 99,999 | 1 | 1 |
| 100,000 or greater | 1 | 1 |
| No response | 1 | 0 |
| Race | | |
| Caucasian | 4 | 5 |
| Ethnicity | | |
| Not Hispanic/Latino | 4 | 3 |
| Unknown | 0 | 2 |

Completion of Study Procedures

All participants who attended the Photovoice Training Session subsequently participated in at least one Photovoice Discussion Session. The absence of any study attrition following training procedures is notable compared to attrition rates found in the brief (i.e. less than 5 sessions) group psychotherapy literature, which ranges from 17 to 57 percent (Yalom, 1995). Participants in Phase I completed fewer study procedures as
compared to participants in Phase II (See Table 3-2). Each of the couples in Phase I completed the baseline assessment, Photovoice Training Session, and the first Photo-Discussion Session. One half of the couples completed a second Photo-Discussion Session; however, data from these sessions were unavailable for analyses. The Findings and Feedback Session was not completed by any of the participants in Phase I. Three of the four couples completed the post-study assessment by mail. Participant attrition can be attributed to study withdraw due to patient declining health, difficulty managing study procedures along with other life responsibilities, and distance from study sessions.

All participants in Phase II completed baseline assessment, Photovoice Training Session, and Photo-Discussion Sessions 1 and 2. Four of the five couples completed the Findings and Feedback Session and post-study assessment. The couple who did not complete these procedures missed the final session and when contacted, the patient reported that she was too ill to complete her participation.

The decrease in attrition in Phase II participants is likely due to adjustments made by study staff to reduce participant travel burden. Given that UF&Shands Hospital serves individuals from across the central Florida region, travel distance was commonly a barrier to study enrollment and participation. In Phase II, a location, day, and time to host our study sessions was chosen that was central and convenient to the majority of our enrolled participants.
Table 3-2. Study procedures completed by participants

<table>
<thead>
<tr>
<th></th>
<th>Baseline Assessment</th>
<th>Training Session</th>
<th>Discussion Session 1</th>
<th>Discussion Session 2</th>
<th>Findings &amp; Feedback Session</th>
<th>Post-Study Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohort B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Couple #16</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Couple #18</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Cohort C</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Couple #19</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Cohort D</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Couple #27</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Phase II</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohort G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Couple #29</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Couple #30</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Couple #31</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Cohort H</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Couple #32</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Couple #33</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

Photograph Assignments

As previously described, participants were given the opportunity to select the photograph assignments for each Photo-Discussion Session in order to ensure the participant-driven nature of this study. Table 3-3 provides a summary of these chosen themes.

Table 3-3. Photograph assignments

<table>
<thead>
<tr>
<th>Assignment Title</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase I</strong></td>
</tr>
<tr>
<td><strong>Cohort B</strong></td>
</tr>
<tr>
<td>Session 1</td>
</tr>
<tr>
<td>Session 2</td>
</tr>
<tr>
<td><strong>Cohort C</strong></td>
</tr>
<tr>
<td><strong>Cohort D</strong></td>
</tr>
</tbody>
</table>
Table 3-3. Continued

<table>
<thead>
<tr>
<th>Assignment Title</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase II</strong></td>
</tr>
</tbody>
</table>

Cohort G

Patient Session 1  How my daily life has changed in the context of ovarian cancer.
Caregiver Session 1 How I helped myself and my wife/partner cope with ovarian cancer.
Patient Session 2  How relationships have changed in the context of ovarian cancer.
Caregiver Session 2 Navigating the healthcare system.

Cohort H

Patient Session 1  How I cope with ovarian cancer.
Caregiver Session 1 What it is like to be a caregiver for a woman with ovarian cancer.
Patient Session 2  Who or what impacts your illness.
Caregiver Session 2 Preparing for a new normal.

**Universal Themes**

**Cognitive and Emotional Sequelae Overview**

The cognitive and emotional sequelae associated with an ovarian cancer diagnosis were described as being vast and fluid. Patients and spouse/partner caregivers reported experiencing a number of difficult, troubling thoughts and emotions including uncertainty, frustration, anger, sadness, anxiety, fear, confusion, shock, doubt, helplessness, irritability, isolation, guilt and regret. However, they also noted feeling hopeful, thankful, reinvigorated, and resilient. The highs and lows and the “rollercoaster ride” of ovarian cancer was often directly dependent upon the patients’ current health status. Participants discussed that their emotional experience was commonly tied to the news that they received at each follow-up appointment. On one hand, positive news could provide encouragement and hope; however, times of joy could also be interrupted by discouragement and disappointment. A later portion of this section will reveal ways in
which patients and spouse/partner caregivers managed these ever-changing thoughts and emotional experiences.

**Uncertainty**

The most commonly reported cognitive schema impacting quality of life in individuals living advanced ovarian cancer was uncertainty. The majority of patients and spouse/partner caregivers discussed that the realities of their lives in the face of ovarian cancer involved an ever-present questioning of “what’s next?” A patient portrayed these ongoing thoughts in her photograph entitled, “Waiting for the Other Shoe to Drop” (Figure 3-1). For most participants, the unknown aspects of the future were more stressful than the known. One woman indicated that the CA-125 marker was a “cloud that hangs over my head.” She reported that even when her test results were encouraging, she wondered how long the positive feeling would last. When this particular patient arrived for her second Photo-Discussion Session, she shared that a second recurrence of cancer had recently been confirmed. For this patient, the period of time between each incidence of cancer varied, and she reflected on how this impacted her thought processes with regard to the future. She described,

> For me it's like a rollercoaster ride. At first I was good for four years and the last time it was nine months, so how long is it going to be the next time? Or am I ever going to get off this stuff? So, it's that rollercoaster ride like, I try to plan things, you know. I try to plan a trip for us for our 40 year anniversary. I have to wait to see how I'll respond to the chemo first. I'm going to wait and see. Everything's kind of on hold while I wait to see how my body will respond to the first couple rounds of chemo. And then I can move on from there. Just have to stay positive. It's just a terrible thing that you have to do.

Spouse/partner caregivers discussed having similar struggles with uncertainty and these feelings in both groups were often associated with anxiety. However, these feelings of uncertainty and anxiety were commonly juxtaposed with a sense of
motivation and drive to cope by making preparations for end of life and to “live today like there’s no tomorrow.”

Figure 3-1. “Waiting for the other shoe to drop”

**Frustration**

In addition to uncertainty, another commonly reported emotion by patients and spouse/partner caregivers was frustration. Frustration was associated primarily with patients’ decreased physical stamina and the resulting lifestyle changes that patients and caregivers endured. For example, one couple, in which both patient and spouse were in poor health, indicated that they felt “Trapped Alive” (Figure 3-2) in their bodies because they had become quite isolated.

Figure 3-2. “Trapped Alive”

The patient stated, “We are alive, but our bodies…We are prisoners in our bodies basically.” For several women who dedicated their lives to maintaining physical health through diet and exercise, they expressed frustration given their lack of control; that
despite their efforts, they became ill with a genetic disease. Many patients also indicated that their feelings of frustration were secondary to the uncertainty of their lives.

One patient described,

This is the third time I’ve had cancer in five years and I have to go through chemo again. And it’s umm, I’m ok with that, it’s just that it’s a little frustrating that you just get your hair back and you have to go through it again. And you wonder how much your body can take.

“Survival Techniques”

Making difficult life adjustments in the face of ovarian cancer required patients and spouse/partner caregivers to employ a multitude of “survival techniques,” as one patient deemed it, or coping strategies.

Use of Humor

One of the most frequently observed coping strategies within the Photovoice sessions was the use of humor. While it was reported by many of the patients and spouse/partner caregivers in Phase I and Phase II, it was most notably observed in the emotional display and interactions among participants within study sessions. Participants frequently made light of their own or their spouse/partner’s mortality. One patient participant laughed when she stated, “My name wasn’t in the paper this morning; it’s a good day!” A spouse/partner caregiver recalled a conversation with his wife about her death,

Some of the questions that come up bring tears to your eyes. Uh, I asked her one time when the numbers were so high and everything, “Are you ready to go?” She said, “Where are we going?” [laughter] I said, “No, we aren’t going out, are you ready to go?” And she said “yes.”

Participants also reported using humor to cope with other difficult aspects of ovarian cancer treatment. One couple described that their family placed wagers and bets each time the patient had her CA-125 measured. Other couples made light of the hair loss
associated with chemotherapy. For example, one caregiver presented the photograph in Figure 3-3, joking that any time the patient changes her wigs, he’ll say, “I’m out with a new lady tonight.”

![Figure 3-3. “My wife’s blings”](image)

**Spiritual/Religious Faith**

Spiritual/religious faith played a large part in the lives of participants in this study. The practice of faith was often tied to feelings of comfort, peace, and thankfulness. Perhaps most importantly, faith was commonly associated with a higher degree of illness acceptance, per participant report. While some participants indicated that they continued to pray for a miracle (e.g., a cure for ovarian cancer), they expressed that they would be accepting of whatever occurred. A spouse/partner caregiver stated, “If it (a miracle) doesn’t happen, we know there is a reason for that.” One patient discussed that when she was initially diagnosed with ovarian cancer, she relied on her faith to cope with this shocking news. This was depicted in Figure 3-4 as she stated,

On the day of the surgery, they were just about to wheel me down and in my door appeared this priest from the hospital out of the clear blue. He asked me if I wanted to be anointed. It’s called the anointing of the sick. I immediately felt this warm feeling through me. I felt very relaxed and almost giddy. They asked me if I was nervous and I said “Not at all.” This was probably the most important thing in my life that I was about to undertake.

Another patient who had been living with ovarian cancer for over fifteen years described that her faith was responsible for the realization that her cancer had actually enhanced
her life. Because she was living with cancer, she stated, she felt she appreciated life more than individuals without a life-threatening disease and attributed this perspective to her faith.

![Figure 3-4. “My salvation”](image)

**Maintaining Personal Identity and Control**

For ovarian cancer patients, it was of utmost importance to combat feelings of helplessness and uncertainty by maintaining personal identity and “life as normal.” A patient participant expressed that she initially felt that she lost her identity to cancer. She said,

> If you don’t control “it” then it will definitely control you. People look at you and think that cancer is a death sentence, but it doesn’t have to be that way. It’s not always that way. I could be further on down. It’s just that we know what we will die of and other people don’t know. When I first got cancer, I felt like the person in The Scarlet Letter with the big “A,” except I had the big “C” on me. And I felt like people were looking at me saying under their breath, “Oh, she’s got cancer.” And that’s not who I was. The cancer was identifying me. I was someone before I had cancer. I’m someone while I had it and you know, I’m someone after cancer.

For women with ovarian cancer, the most effective way to preserve their identities was to remain engaged in their prior relationships, occupational endeavors, and recreational activities to the highest extent possible. Given the high demands of treatment and the associated painful side effects, this was often achieved by making adjustments to prior activities to accommodate changes in their physical well being. Many of the women
continued to work throughout the course of ovarian cancer treatment while making necessary adjustments. One patient made accommodations by not only scaling back her client load in her personal business, but also having invoices faxed to the infusion room while receiving chemotherapy in order to simultaneously complete her work activities. Another patient reported that continued involvement in her work was “a savior, mentally” as it allowed her to maintain her independence. One woman, determined to “not let the whole day be a chemo day,” decided to schedule all of her chemotherapy appointments in the morning so that she could fill the remainder of her day with more desirable activities. Independent of the ways in which this was achieved, women in this study globally acknowledged the realities of their diagnosis but wished to “add cancer to my life, not make it my life.”

“Sadness Diversions”

Similar to maintaining personal identity and continuing to engage in enjoyable activities, the use of distractions or “sadness diversions,” as one caregiver named it, was a helpful coping tool for many participants. A caregiver who was physically limited due to illness reported that he used his computer as both a distraction and a way to remain in contact with others. Remaining active in exercise was a way for patient participants to distract themselves and to combat treatment side effects like weight gain. One patient described that her swimming pool was a relaxing place to compose her thoughts and that swimming allowed her to “get in my own world and forget that I have cancer.” Similarly, a caregiver stated,

There is no real eureka button to press to change sadness to happiness. It is what it is and we have to deal with it. So, what I was thinking for myself and her is that I would be looking for sadness diversions. So, something that would create a smile that would just lose our mind from our focus, from our anxieties, from our worries.
One such diversion involved the weekly purchase of lottery tickets ("Daydreams: One dollar each" [Figure 3-5]). For this couple, it provided a light-hearted moment to reflect on the “what if?” aspects of winning the lottery.

Figure 3-5. “Daydreams: One dollar each”

Making Preparations

Women in this study also reported that making future preparations was an important way in which they could actively cope with and manage the difficult realities of their lives. Because all of the women were married/partnered and most had children, it was crucial for them to plan ahead to ensure the well being of their families. One patient who emphasized the importance of a healthy diet in the home wanted reassurance from her husband that her family would continue to eat nutritious meals after she passed away. Another patient reported that she was making preparations for end of life, funeral services, and future for her husband in order to decrease the burden on him. She described that she was currently in the process of having her siblings choose photographs and music to be displayed at her funeral services and that them doing this was a “gift” to her as she believed it would make things easier for her husband. Additionally, she noted that she secured a place for her husband to live with extended family and has worked to prepare him for life without her by saying, “you don’t have to die because I die.”
Social Support

Common across both patients and caregivers in Phase I and Phase II were themes regarding the importance of social support during the cancer experience. Many of the patients reported that they attributed much of their success in living with cancer to the support of their spouse/partner caregiver, family, and friends. One couple stated that given the immense support they received, they pitied anyone coping with cancer who did not have a strong support network. As one patient described when discussing her group of supporters,

Without that group, and we have a group of friends in our church, I am not sure I would have made it through. I think I would have made it through, but I wouldn’t have made it out on the other end as well as I did. I never would have done that without the people surrounding me and the support system.

Specific Supporting Roles

Similarly, additional patient participants discussed that their support community enhanced the quality of their experiences in coping with a cancer diagnosis by serving in a variety of roles. The patients reported that the support they received emerged from a number of communities including family, friends, churches, neighborhoods, medical staff, and even fitness centers. One patient discussed that she not only received spiritual and emotional support from a group of women from her church, but she was also engaged in weekly Bible study that provided her with the intellectual stimulation that she desired. Several of the women, determined to maintain normalcy, made efforts to continue their physical exercise routines following diagnosis of ovarian cancer and throughout their treatment. Given their regular attendance, they described that gym members and staff became a part of their support teams and were especially useful in
providing motivation to stay active. On variations in supportive roles, one patient stated, “I compensate with just different people in different categories for different things.”

The patient participants were eloquent in their descriptions regarding the individuals who provided them social support and the unique ways in which these individuals supported them. One patient expressed that her supporters were “heroes” and stated, “I was at the top of the pyramid and they are all pushing me onward.” The “extraordinary heroes,” as she described, were her inner circle of family and friends and represented qualities including “giving, caring, blessing, and loving.” This inner circle was comprised of close friends and family who were thoughtful (e.g., sending the patient’s favorite flowers), telephoned on a daily basis, and/or provided instrumental support (e.g., brining groceries to their home). The “ordinary heroes” were also important supporters, but tended to be acquaintances as opposed to those with which she had close relationships.

Another woman likened her support system to a “team.” One of her photographs was entitled “The Coach of My Team” and portrayed her oncologist. She stated, “He is such a motivator. He’s just like a coach. He’s so inspirational and positive.” The patient then expressed that her “Pep squad or booster club” was a group of individuals who were always available to assist her by providing transportation to medical appointments, attending church with her, or engaging in recreational activities. Her “Shining Stars” included her daughter, her eldest son, and their families. She noted that each of them was supportive in unique ways, with her son providing distraction through humor and her daughter and son-in-law conducting research and assisting her with informational needs. Lastly, her “Foundation” consisted of her youngest son and her husband. Given
her husband’s occupational demands, her youngest son moved into their home and provided her with instrumental support while she underwent extensive chemotherapy.

When discussing supportive roles, caregivers had a tendency to discuss their appreciation for support that served primarily as distractions from the realities of their lives as opposed to emotional or instrumental support. This was illustrated by one of the photographs that a caregiver selected to discuss in a Photo-Discussion Session (Figure 3-6) in which he described ways in which he managed feelings of depression and anhedonia in response to his wife’s ovarian cancer diagnosis. The photograph of his car was entitled “Back to Life” and he discussed that he removed the engine shortly prior to his wife’s diagnosis. Repairing his car, as he stated, was a way for him to re-immerses himself in his hobbies and to return to normalcy. His nephew traveled on several occasions to assist him in restoring the car and he noted that his relationship with his nephew strengthened significantly during this time. As he discussed his relationship with his nephew and the positive feelings associated with this accomplishment, he became tearful and stated that this emotional reaction was unexpected.

Figure 3-6. “Back to life”

**Unique Spouse/Partner Caregiver Role**

While all supporters in the patients’ lives served specific roles, it was evident from both patient and caregiver discussion that the spouse/partner caregiver filled a
special, unique role. One patient explained that her supporters were “a pyramid of strength” with her husband being the leader as “the peak of the pyramid.” Unlike the support of family, friends, or other community members, the spouse/partner caregiver was the constant support. One couple was married between the patient’s initial diagnosis and treatment and her first recurrence, providing her perspective on living with ovarian cancer with and without a spouse/partner caregiver. She described,

The first time I basically went through it alone. I had friends and family that flew in and took care of me for four or five days and went home and then someone else would come, but he was there for me. He is my rock.

Spouse/partner caregivers also recognized this unique role, noting that simply being present was the most important aspect of this role. One caregiver stated, “I am more, I think, of a comfort and a foundation and a pillar for her personally in the home setting.” This particular caregiver had earlier discussed feelings of guilt and regret regarding his decision to prioritize achieving his career goals over maintaining presence for his wife. Over the course of participating in the study and speaking with another caregiver who made significant efforts to be present for his wife, this caregiver ultimately decided to retire in order to be a bigger part of his wife’s daily experience.

In addition to maintaining a constant presence, spouse/partner caregivers served in other unique roles including “the fixer,” “the motivator,” “the informer,” and “the limit setter” all while attempting to balance other roles in their lives. As one caregiver described in his photograph (Figure 3-7),

One is a picture of a girl in the garden and standing there with her hands out represents trying to balance the reality of cancer and living with cancer and your responsibility to family and your job and other people who depend on you. And many days you feel like a statue. You’re frozen. You wish you could lift something higher or let something down, but you can’t. It is not a sad thing necessarily; it is just the reality of someone trying to be a caregiver, survivor, and a fixer.
Given the necessity to maintain this balance, caregivers indicated that as a spouse/partner they felt at times as though they had “sole responsibility.” For example, they noted that they often had to bear the burden of communicating the patients’ updates to other family, friends, and supporters. While all spouse/partner caregivers willfully embraced the role of primary supporter in the face of their wife or partner’s ovarian cancer, it was clear that they experienced an emotional toll as a result.

**Emotional Impact of Serving as Spouse/Partner Caregiver**

Aside from the fear and uncertainty associated with an ovarian cancer diagnosis, spouse/partner caregivers frequently reported experiencing feelings of confusion and loneliness in response to adopting a new caregiving role. One caregiver stated,

> And sometimes you feel very alone. We have family across the yard and friends all over, but you still feel like…You’re the one she says “peak of the pyramid.” I feel like it’s the foot stool. Everything comes to rest here. Not that you don’t want to deal with it, but you wish you could deal with it better. You wish you were smarter, you know, you wish you made all the right decisions every day. Life just isn’t like that, so it equals a lonely, cold, inflexible position you find yourself in.

Similarly, spouse/partner caregivers placed strong emphasis on discussing the fact that they felt unprepared and confused in their role as caregiver. One caregiver described that he struggled with the stress of trying to understand the patient’s perspective while managing his own difficulties. Another caregiver stated, “There is no clear path” or
“guide” to being a caregiver and that he “didn’t know how to react to everything.”

However, despite these difficulties, spouse/partner caregivers uniformly deferred their own needs in order to support their wives/partners, describing that their role was to simply “ease the journey” for the patients. For an older caregiver with significant chronic health problems of his own, this meant putting management of his healthcare on hold until his wife’s health had improved. Another spouse/partner expressed that he repressed and avoided discussing his own emotional reaction to cancer in order to “protect” his wife/partner. The following excerpt from a Photo-Discussion Session in Phase II also illustrates this caregiver’s denial of his own needs,

I wondered if she goes ahead of me, how it will affect me because there is no family here and I guess I shouldn’t even look at it that way. I should be more concerned about what’s going to happen with her than what will happen with me.

Patient Observation of Spouse/Partner Caregiver Struggle

Patient participants in both Phase I and Phase II communicated that their spouse/partner caregivers’ struggle with their cancer diagnosis did not go unnoticed. Given that the majority of patient participants were accustomed to serving in caregiving roles, it appeared that this allowed them to appreciate the struggles endured by their spouse/partner caregivers. Below is an excerpt from a discussion among two patients,

Patient 1: I think sometimes for the caregiver the stress level on them is greater than on the patient. We are having the physical stress and the mental feeling with the cancer, but they have the emotional…

Patient 2: And they can’t do anything to make it better.

Patient 1: Right and they can’t do anything to fix it. You know they can’t fix it. They can’t snap their fingers and make them well.

Patient 2: And it is the husband’s role to fix it, to make it better.
Patient 1: Right, yeah, so I think for them...I feel sorrier for him than I did for myself by far.

In addition to pitying the role of the spouse/partner caregivers, patients were also concerned that the caregivers’ needs were minimized by others. For example, one patient noticed that few supporters inquired about her husband’s well being when they telephoned her. Based on their reports, it appeared that the patients were aware of their caregivers’ difficulties not because these were directly communicated to them; rather, through observation and firsthand experience. One patient joked that her husband “stalked” her by repeatedly telephoning her when he was out of town on business to manage his own anxieties. Another patient confided that given her husband’s fear, his support was at times “stifling” and “too present.” Caregiver hypervigilance provided an additional difficult set of circumstances for the patients to navigate as they expressed uncertainty in how to respond to this manifestation of caregiver anxiety. These phenomena will be further elaborated upon as they are related to a phase-dependent theme.

Life Changes in the Context of Cancer

Changes in Relationships

Participants in Phase I and Phase II revealed that one of the most significant changes they experienced that resulted from living with ovarian cancer was in their personal relationships. With regard to their romantic relationships, many participants reported that their relationships with their significant others strengthened as they experienced cancer together. Several couples described that they “bonded” over shared experiences and the “role reversal” that occurred. One patient who lived and worked with her partner discussed that she gained a greater sense of trust in him,
I always took care of him and tried to make sure that he was ok. It’s my office, my business, and he came into my business and started working for me. I always took care of things and took care of him. He took care of things in a different way. You know, every morning, he always has my coffee ready for me to pick up and get into the hot tub. So, he took care of me in that way, but when everything happened with the cancer, I think it was just such a shock that I tried to kind of shut him out from the medical stuff. I didn’t want him to come to the doctor’s appointments because I didn’t think he’d handle it well. I tried to insulate him. So when I ended up in the hospital for my surgery and I was out of work, he had to take care of everything at home and the office. For me, I realized, “wow, he not only can but wants to do this.” So that kind of changed things when I started getting better. I emotionally am more open about things and as far as responsibility-wise, I feel more comfortable allowing him to handle things. From our perspective, I feel like we had a very strong relationship to begin with, but it was certainly made stronger by far from this experience.

Several patients and caregivers indicated that their relationships with family and friends also strengthened in the face of cancer. In some instances, these relationships changed for the positive because family and friends made efforts to increase their communication and support during this time. Some said family members that were estranged reemerged following the cancer diagnosis. In addition, patients and caregivers also placed more emphasis on the quality of their relationships and prioritized spending their time with individuals with whom they had healthy relationships. Many described that having cancer forced a “shaking out experience”, “filtering out” or “letting go” process as they learned discernment for healthy and unhealthy relationships. Several participants indicated that the realities of relationships were revealed and that while some strengthened, some “fell apart.” For example, one patient recalled that she put significant effort into meeting a friend for lunch (i.e., driving long distance and going despite feeling ill) and that she had not been in contact with that friend since that time because, “She never once asked me how I was doing.” On the other hand, one couple reported that they chose to end relationships with individuals whom they felt focused too
heavily on discussing one another’s health because the patient was “tired of talking about cancer all of the time.” Lastly, another patient described,

I now feel like I’m making the choice to have them (relationships) on my own terms. And that I’m better at setting boundaries and I’m more outspoken about the things that I’m not pleased about and I don’t worry about the consequences of that like I used to.

Overall, despite the reason for change, the shift in relationships was strongly associated with participants’ desire to make the most out of their remaining time, albeit however uncertain that amount of time was.

Increased Meaning

Many patients and caregivers reported that they found greater meaning in the day-to-day realities of their lives in the context of ovarian cancer. This increased sense of meaning emerged from an adaptive coping strategy to actively search for “the good in the bad” and with this change in thought processes came a greater appreciation for “the small things in life.” One couple said that ovarian cancer “reinvigorates you internally about celebrating life” and many participants described that they put significant effort into searching for opportunities to create memories together each day. Several photographs taken by participants depicted their greater appreciation for natural beauty including scenes of trees, gardens, sunsets (Figure 3-8), and beaches.

Figure 3-8. “Sunsets on the Gulf”
Each day provided an opportunity to marvel at these scenes together and for spouse/partner caregivers especially, the concept of time held a greater meaning in the context of cancer. As one caregiver indicated, “Each calendar represents little chunks of life” (Figure 3-9). Not knowing how many of these calendars remained for his wife motivated this caregiver to metaphorically put himself on her calendar in order to be as present as possible and to make the most of their time together.

![Figure 3-9. “Little chunks of life”](image)

**Changes to Priorities/Values**

Related to an increase in efforts to search for meaning and appreciation for natural beauty, many participants reported that with the addition of ovarian cancer to their lives came changes in their priorities, values, and even personalities. This was discussed less frequently in spouse/partner caregivers, although they did note that they developed a greater appreciation for their relationships with their wives/partners, began to focus more on enjoying each day, and experienced a strengthening of religious/spiritual faith. Patient participants reported experiencing these in addition to several other changes in the context of cancer. A woman with a history of both breast cancer and ovarian cancer described that her values and priorities underwent a greater change in the face of ovarian cancer because the diagnosis was “more of a shock.” The diagnosis was more shocking to her as her mother had a history of breast cancer, so she stated that her own diagnosis of breast cancer was not surprising. Another
patient indicated that she began to center her life more around her own preferences as opposed to making decisions to please others. An increase in taking more time for themselves was common in many of the women and some even described that they felt they were “better off” given the unique outlook on life that ovarian cancer provided. For instance, a patient stated,

I have to say that the whole experience of having cancer has made me a better person and I feel blessed because it makes you prioritize things in your life and it makes you look at things differently and treat people differently and you listen more to what people are saying. You don’t blow people off and you try to be more forgiving which is very hard to do sometimes. You try not to let things upset you and you try to always focus on the positive. For me it was a difficult thing because I’m kind of a realist, so I tend to focus on, “well this could happen or this could happen” and so now I focus on what could go right and things like that. I had to prioritize things in my life and my relationships and I had to let some things go and forgive, and plus, it’s brought some very nice, wonderful people into my life that I wouldn’t have met otherwise. And so I’m thankful for it and I turned myself around religiously. I turned myself over to Jesus and I had a wonderful religious experience and that has helped me a lot. So, I’m just a different person than I was five years ago.

**Discourse on Healthcare**

One of the most commonly discussed themes across all participants was the integral role of healthcare providers, particularly physicians, in the quality of their experiences with cancer. Approximately 44% of both patients and spouse/partner caregivers recounted instances of negative experiences with physicians during the course of treatment for cancer. These were commonly associated with feelings of anger, frustration, and lack of trust. As one patient described her initial oncologist, “If I had to pick two to three people in my life that I’ve ever come in contact with that were horrible, he would be one of them.”

Patient and spouse/partner caregiver participants were vocal about their opinions regarding desirable and undesirable qualities in a physician. There was a strong
preference for providers who are straightforward and honest about patient health, particularly prognosis. It was described that “sugar coating” can lead to “false hope;” whereas, direct feedback allows the patient and family to adjust and actively cope with the circumstances. Additional positive qualities in a physician included use of clear explanation, respectfulness, willingness to answer questions, taking pride in their work, and “confidence without arrogance.” Participants described that these interpersonal characteristics were directly tied to the trust in which they had in the providers. One of the photographs taken by a spouse/partner caregiver and discussed with group members as a fulfillment for the assignment entitled, “Navigating the Healthcare System,” illustrated this sentiment. Depicted in the photograph is a pair of cufflinks with the words, “Trust me….I am a doctor.” The participant titled this picture, “Earned, Not Given” (Figure 3-10). He further described,

The title is talking about trust. You can’t just give out trust looking at a curriculum vitae. That’s for everyone in any discipline. So the description, trust is not something given based on a CV, rather by action. And it’s not action in the past necessarily; it’s how you carry yourself. You can usually make a very good impression just in the first two minutes. When making a first impression, you are looking for someone to open up and show who they are. Now they may have some idiosyncrasies, but it’s about showing who you are instead of seeming like you’re holding something back or putting on a show. The way they carry themselves, how they treat you, and also whether they are on time, courteous to your time, these are all things that will help create that trust.

Figure 3-10. “Earned not given"
The spouse/partner caregiver participants further discussed that this process of building trust in the first encounter is especially crucial when working with specialists given that they felt there were fewer opportunities in these instances to develop trust as compared to those with a family or primary care physician. Having a positive, trusting relationship with healthcare providers was imperative during the cancer experience because as one caregiver stated, “Cancer happens so fast.” Indeed, both patient and caregiver participants reported that they experienced less anxiety when they had providers they felt they could trust. One patient explained,

If you don’t have a doctor who is positive and upbeat then forget it! Because there are people who don’t have them. I know people and it’s just so disruptive to your treatment and upsetting if you can’t call them and confide in them.

Another patient described that given the large amount of time that she spends in medical settings for cancer treatment and follow-up, that her doctors have become a part of her family and have enhanced her experience.

**Ovarian Cancer-Specific Concerns**

Cancer antigen 125, often referred to as CA-125, is a tumor marker measured through blood draw (National Comprehensive Cancer Network, 2008). In ovarian cancer, it is typically used in both the diagnosis of and monitoring of response to treatment. Unfortunately, however, CA-125 testing has several flaws in that it is difficult to detect in early stage ovarian cancers and can produce false-positives. In the absence of specific study questions targeting this issue, approximately two thirds of the women in this study expressed their frustration with the lack of more comprehensive and accurate testing procedures for ovarian cancer. One patient participant called it, “just trash.” Their dissatisfaction with the lack of accuracy was further perpetuated by their belief that
detection of breast cancer through mammography was not only more precise, but also more widespread. A participant who had a history of both breast cancer and ovarian cancer stated,

What I would love to see one day is that my nieces, that they don’t have to wait until stage III. That there aren’t many tests prior to getting ovarian cancer, and unless you have a good doctor that finds something early because the symptoms are so mild.

There was significant desire for more timely and accurate detection of ovarian cancer for future generations. As a result, this was one of the factors driving women in this study to seek out opportunities to increase awareness and advocacy efforts in the ovarian cancer community.

Summary of Universal Themes

Please refer to Table 3-4 for a summary of the aforementioned universal themes.

Table 3-4. Summary of universal themes

<table>
<thead>
<tr>
<th>Factors Impacting Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive and Emotional Sequelae</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Life Changes in the Context of Cancer</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Discourse on Healthcare</td>
</tr>
</tbody>
</table>

Means to Improve Quality of Life

“Survival Techniques”       Use of Humor
                           Spiritual/Religious Faith
                           Maintaining Personal Identity and Control
                           “Sadness Diversions”
                           Making Preparations

Social Support               Specific Supporting Roles
                           Unique Spouse/Partner Caregiver Role
                           Emotional Impact of Serving as Spouse/Partner Caregiver
Phase-Dependent Themes

Burden of Support

The most noteworthy and informative phase-dependent theme that emerged was the discussion among Phase II patients regarding aspects of social support that can be burdensome. As previously elaborated upon, social support played an integral role in the lives of patients and spouse/partner caregivers who were impacted by ovarian cancer; however, when patient participants were provided the opportunity to reflect upon their experiences independent of their caregivers (i.e., Phase II), they revealed what appeared to be a more honest commentary on support. Specifically with regard to relationships with significant others, two of the participants stated that separating patients and caregivers during the Photo-Discussion Sessions was helpful as they said, “The caregivers have their own issues. It’s hard to deal with his issues too.” One patient felt that her husband struggled in balancing his own concern versus the need to support her appropriately; however, she was unsure how to communicate this to him without being “disrespectful.” To further illustrate these difficult circumstances is an excerpt from a discussion in which the patient presented a photograph of her dog (Figure 3-11),

Figure 3-11. “Comfort”

Patient 1: My dog was with me during my breast cancer. He’s 12 now. This represents when you’re going through chemo and this stuff, hug something. Hug a teddy bear, hug your husband, but the thing is, I don’t always want to hug a human being. You know when you’re going through chemo, you really don’t want to be touched.

Patient 2: Right!
Patient 1: But when I’m with my dog, it’s that comfort. He doesn’t ask any questions like, “Are you ok?”, “Did you drink enough?”, “Did you eat?”, “Did you go to the bathroom?” I hate that. I don’t know about you guys, but I hate it.

Patient 2: Your dog knows exactly how you feel, huh?

Patient 1: Exactly. He knows when to be there and when not to be there. So for anyone going through something like this, grasp onto something. Sometimes we don’t want to say we don’t want to be touched because we don’t want to hurt the caregiver.

Patients also discussed experiencing feelings of frustration with regard to the response of friends and acquaintances to their cancer diagnoses. Several women discussed that maintaining their personal appearances in public was both positive and negative. On one hand, it boosted their self-esteem to feel as if they looked well; however, they felt that when they “looked good,” there were some individuals who did not understand or appreciate how ill they actually were. Many women expressed that in the work environment or social settings, they received an abundance of unwarranted advice, questions, and anecdotes. One patient described,

I really didn’t look sick, but basically people didn’t understand that when I stripped off all of this, people didn’t even recognize me. Another thing – people would describe, “Oh this person I know...” and then tell me that that person died of the cancer. Or knowing a person who has had cancer and what they’d gone through. I felt guilty that I didn’t want to hear it, but I really didn’t want to hear it. I had my own struggles and I didn’t want to hear about others’ struggles. Emotionally, I was dealing with my own struggles.

One participant endured this to the extent that she compiled a list of “Things Not to Say to a Cancer Patient.” In addition to statements previously mentioned, also on this list were questions/comments from others including, “When do you move on and forget about it?” and “I understand.” She stated,

The next statement: “I understand.” You can probably relate to this. Hearing from another cancer survivor of maybe a more curable cancer telling me they understand because they had it. Because we feel as a group that you couldn’t possibly understand.
Receiving these comments from others, despite well-meaning intent, only further exacerbated the emotional struggles of women in this study. Not only were they managing their own difficulties, but with unwarranted support, they were burdened with the responsibility of commenting on or declining this information without being hurtful.

**Advocacy**

Patient participants in Phase II engaged in significant discussion regarding their growth as personal and community advocates for ovarian cancer. A patient who dedicated her time to the public policy sector and increasing education regarding ovarian cancer described that her cancer diagnosis prepared her to become a better advocate. She discussed that prior to her diagnosis, she was “ignorant” regarding the medical system and tended to “blindly follow doctor’s orders.” Following a series of negative experiences with healthcare providers, she reported that she became aware of her need to educate herself and to demand fair treatment from her providers. She further explained,

> I say it was such a learning experience because I felt so ignorant about all of this prior to, and then I finally saw. You know, I’m an educated lady and I saw them treating me this way and thought, how are treating the poor, uneducated ladies? And it enraged me to be honest. What it did was it made me realize that there were people out there less fortunate than me and that I needed to give them a voice. So, everyday I talk to people who call me and confide in me about different things that they have going on and issues that they have and they ask me about my perspective. And then I explain to them my perspective and how I dealt with things and then I ask them to keep the chain going and to tell their friends and so on. Really, I want us to start uniting and let doctors know that if they aren’t going to give us what we deserve, then we’ll go elsewhere.

For patient participants in Phase II, passing along information to other women in their communities was a way to “give back” and to cope with their cancer by transforming a negative emotion into positive action. They discussed that their activism helped combat
feelings of helplessness. Many of the women devoted time to participate in speaking engagements at local chapters of various cancer organizations and mentoring other patients. Additionally, spouse/partner caregivers in Phase II discussed their dedication to advocating for the patients due to their “duty to be informed and involved, just like the patients.” For caregivers, this meant diligently taking notes during medical appointments, asking questions, problem-solving difficult situations as a team with their wives/partners, being proactive, supporting the patients in their community education efforts, and “navigating the system.”

**Learning to navigate the system**

Learning to get their needs met within the healthcare system was of utmost importance to several of the spouse/partner caregivers in Phase II. In fact, “Navigating the System” was chosen as one of the Photo-Discussion Sessions and was illustrated using photography. One caregiver described that throughout his experience with his wife’s ovarian cancer, he learned that the healthcare system consisted of two parts: medical and financial. The photograph of the flower bulb (Figure 3-12) represented “The Beginning;” the process of attaining all of the necessary information in these two areas.

Figure 3-12. “The beginning”

Over time, he learned that navigating the medical aspects of her care involved becoming informed, asking the difficult questions, and ensuring that all of his wife’s providers were “in the loop” regarding her care. He also acknowledged the difficulty in
managing financial matters during cancer treatment as he learned to become an advocate for his wife by taking initiative, holding billing companies accountable, and asking for help when necessary. He described,

I called them up and asked if I could get any assistance because I owed 1,200 dollars. They actually told me they would cover it. That’s something I realized is that if you’re under hardship and don’t think you can pay it, you can ask for that and the worst they can say is “no.” There are a lot of tools out there that I wasn’t aware of.

His second photograph in the series, entitled “Knowledge Bloom” (Figure 3-13), was a representation of his process of developing into an advocate over time.

Discussion of Fear

Participant discussions regarding fear varied between Phase I and Phase II. In Phase I, in which couples participated in discussion sessions together, several patients reported feelings of fear tied to leaving their loved ones, particularly the caregivers, behind. One patient whose husband was also very physically ill stated that her fear of not being present for her husband was more difficult than thoughts of her own death. Similarly, another patient expressed,

Right now the only things I’m scared about in all this is leaving all these cool people and stuff. Mostly him and my daughter. But mostly him. My daughter will be ok. I know she’ll find someone to be there for her during all those hard times. He’s the one I worry about more.
While patients did not discuss fear in Phase II, some of the caregivers shared fear of their wives’ deaths. Although cancer recurrences were expected, they feared “when it would take its toll.” One caregiver expressed that he feared being alone when his wife passed away and that their alarm clock represented this fear (Figure 3-14). He stated,

With the pictures of the clock here, we were in bed and the alarm went off and it kept ringing and ringing and ringing. And no movement on the other side of the bed. That’s why we have this picture. I reached over and tapped her and there was no response. Then I tapped her harder and there was a response and that’s how I knew she was alive. But when she didn’t respond for so long, I thought I had lost her. I was afraid she had passed away.

Notably, this fear was not discussed by spouse/partner caregivers in Phase I among dyadic groups.

Figure 3-14. “We don’t know how much time we have”

**Frustration with Lack of Attention to Gynecologic Cancers**

Lastly, one of the largest discrepancies among Phase I and Phase II was in the amount of discussion regarding the paucity of research and support for women with gynecologic cancers. While this was not a topic of conversation in any of the Phase I sessions, it was quite prevalent in Phase II, both in patient and in spouse/partner caregiver discussions. Women in Phase II often reported feelings of frustration and isolation given the lack of attention to gynecologic cancers both in the medical
community and in the media. Specifically, they frequently acknowledged the magnitude of the representation of breast cancer in these areas as compared to gynecologic cancers. One of the patient participants stated, “We feel like the forgotten bunch. See, even your colleague in there was wearing the pink bracelet, but you didn’t see the teal one. We feel forgotten that no one wants to talk about it.” Spouse/partner caregivers reported that they felt a lack of support not only given the gynecologic cancer diagnosis, but also due to their caregiver status.

**Summary of Phase-Dependent Themes**

Table 3-5 provides a summary of the phase-dependent themes.

<table>
<thead>
<tr>
<th>Factors Impacting Quality of Life</th>
<th>Means to Improve Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burden of Support</td>
<td>Advocacy</td>
</tr>
<tr>
<td>Fear</td>
<td>Learning to Navigate the System</td>
</tr>
<tr>
<td>Frustration with Lack of Attention to Gynecologic Cancers</td>
<td></td>
</tr>
</tbody>
</table>

**Participant Commentary on Photovoice**

The Findings and Feedback Sessions held with the participants were quite informative with regard to the acceptability of Photovoice procedures and their specific thoughts about the discussions in which they engaged. None of the participants reported that the Photovoice procedures were intrusive or unpleasant. Approximately one half of the participants expressed that they initially had some hesitancy and/or confusion regarding the study procedures given that this experience was unlike anything in which they had been involved in the past. This feedback suggests that more comprehensive and concrete information should be provided in future Photovoice training sessions.
Despite reports of initial uncertainty, the majority of the commentary received was quite positive. In fact, across both of the study phases, patient and spouse/partner caregivers alike reported that the Photovoice sessions were enjoyable and oftentimes therapeutic. Couples in Phase I and Phase II stated that the study procedures engendered personal growth by broadening their abilities to openly discuss their emotions and therefore improving communication in their spousal relationships. A patient who participated in Phase II stated, “Expressing my feelings, that’s another thing – through this experience I’ve learned to express myself and not feel ashamed about it.” During the concurrent Findings and Feedback Session, this patient’s husband expressed that the discussion fostered during study procedures improved communication with his wife and motivated him to make a significant life change,

I will say this experience, or parts of it, prompted an opening, a level of discussion that I hadn’t had. Not even with my wife. And I think I read somewhere that that was part of the goal. So I had to say to myself, am I or not? So, I did. I will say this, if there is any benchmark on how you can define the value for me personally, it was probably by the second meeting in, this experience helped me to finalize the decision to retire. That is significant because I had been trying to find ways to avoid doing that.

Given the difference between Photovoice and traditional methods of both qualitative inquiry and support groups, participants were asked to reflect on the usefulness of photography to discuss their experiences. Participants varied in their response to the request to engage in photography. For some, artistic expression was a former hobby; however, other participants expressed apprehension and even feelings of intimidation with regard to photographing their experiences. Ultimately, the majority of participants reported that the photographs provided a catalyst for the discussion of difficult and sometimes avoided topics. None of the participants suggested that the Photovoice method was inappropriate or unhelpful.
Several of the participants expressed their appreciation regarding the fact that ovarian cancer was receiving focus in the literature and were pleased to have been involved in the study for this reason. One caregiver stated,

I realized I’m not alone; she’s not alone. We are very active in our local cancer organization but she’s the only survivor. When she has issues or questions, she doesn’t have anyone she can bounce ideas off of. Doctors say one thing, but it’s not what you’re feeling and someone else may give better advice about resources. She’s beginning to understand that she’s not alone and that there are others around. This project helps bring us all together.

Lastly, suggestions were received as to how to improve upon study procedures. A patient participant in Phase II who reported having an overall positive experience recommended that study staff enforce a time limit to Photovoice sessions and ground rules stating that all points made were valid. This participant also expressed a desire to have larger cohorts in order to gain exposure to a wider variety of experiences. These comments were suggestive of a negative interaction between patient participants within the cohort and although it is believed that this was the only occasion of this nature, it is important feedback for facilitators to remain cognizant of in the future.

Exploratory Aims

In addition to our efforts to describe the experiences of individuals impacted by advanced gynecologic cancers through qualitative methods, an exploratory study aim was to quantify the extent to which our procedure of inquiry (Photovoice) was therapeutic or beneficial to the participants.

Mood Disturbance

The condensed version of the Profile of Mood States, or Mini-POMS, (McNair, Lorr, & Droppleman, 1981) was completed by participants at multiple time points during the course of their involvement in the study. However, in order to broadly assess
differences in mood disturbance from initial study procedures (i.e., Photovoice Training Session) to completion (i.e., each participant’s final session), effect size differences were calculated. The maximum possible score on this measure was 20, suggesting extreme mood disturbance (i.e., extreme levels of anger, anxiety, depression, fatigue, and confusion) and the lowest achievable score was -4. A negative score not only illustrated the absence of the aforementioned symptoms, but the presence of vigor (i.e., energy). Table 3-6 illustrates these findings.

**Table 3-6. Effect size differences in mood disturbance pre- and post- study Participation**

<table>
<thead>
<tr>
<th>Phase I</th>
<th>Pre-Photovoice Mini-POMS Mean (SD)</th>
<th>Post-Photovoice Mini-POMS Mean (SD)</th>
<th>Effect Size (d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients (N=3)</td>
<td>-0.67 (2.31)</td>
<td>-0.33 (1.53)</td>
<td>-0.18*</td>
</tr>
<tr>
<td>Caregivers (N=3)</td>
<td>2.67 (4.73)</td>
<td>-0.33 (4.04)</td>
<td>0.68***</td>
</tr>
<tr>
<td>Phase II</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients (N=4)</td>
<td>-0.75 (3.95)</td>
<td>-1.50 (1.73)</td>
<td>0.26*</td>
</tr>
<tr>
<td>Caregivers (N=3)</td>
<td>0.75 (4.99)</td>
<td>-2.75 (1.25)</td>
<td>1.12***</td>
</tr>
</tbody>
</table>

*Note: * = small effect size, ** = medium effect size, *** = large effect size

**Phase I**

The results suggest that while patient participants in Phase I generally denied any negative mood symptoms ($M = -0.67$, $SD = 2.31$), spouse/partner caregivers endorsed having some mild mood concerns ($M = 2.67$, $SD = 4.73$). Calculation of Cohen’s $d$ revealed a large effect size difference ($d = -0.95$) between the two groups in baseline mood disturbance. Not surprisingly, spouse/partner caregivers also experienced a greater change in their mood symptoms pre- and post-Photovoice participation, demonstrated by a large effect size ($d = 0.68$). There was a small effect
size and trend in the patient participants towards worsening mood following Photovoice participation ($d = -0.18$).

**Phase II**

Similar to the findings related to Phase I participants, spouse/partner caregivers reported a greater number of negative mood symptoms upon study entry ($M = 0.75, SD = 4.99$) as compared to patient participants ($M = -0.75, SD = 3.95$). This effect size difference was medium ($d = -0.34$). On average, there were fewer symptoms of mood disturbance reported by both patients ($M = -1.50, SD = 1.73$) and caregivers ($M = -2.75, SD = 1.25$) post-Photovoice participation. This suggests that patients ($d = 0.26$) and caregivers ($d = 1.12$) experienced improvements in mood following study procedures, with small and large effect size differences, respectively.

**Patient quality of life**

The Functional Assessment of Cancer Therapy – Ovarian (FACT-O) was used to assess patient quality of life (Basen-Engquist et al., 2001). The sum of all items generated a total quality of life score. The range of potential scores is 0 to 156, with *higher* numbers signifying *higher* quality of life. Patient participants in Phase I and Phase II entered the study with nearly comparable ratings of quality of life. Patient participants in Phase I reported experiencing a decrease in quality of life following study participation, with this difference demonstrating a small effect size ($d = 0.28$). In contrast, quality of life ratings for women in Phase II remained constant pre- to post-Photovoice participation ($d = -0.04$), suggesting no change in quality of life. Table 3-7 summarizes these results.
Table 3-7. Effect size differences in patient quality of life pre- and post- study participation

<table>
<thead>
<tr>
<th></th>
<th>Pre-Photovoice Mean (SD)</th>
<th>Post-Photovoice Mean (SD)</th>
<th>Effect Size (d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase I Patients</td>
<td>81.33 (3.21)</td>
<td>79.33 (11.24)</td>
<td>0.28*</td>
</tr>
<tr>
<td>(N=3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase II Patients</td>
<td>81.75 (5.91)</td>
<td>82.00 (5.57)</td>
<td>-0.04</td>
</tr>
<tr>
<td>(N=3)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: * = small effect size, ** = medium effect size, *** = large effect size

Spouse/partner caregiver quality of life

Spouse/partner caregivers completed The Caregiver Quality of Life Index – Cancer (CQOLC) in order to measure quality of life pre- and post-Photovoice participation (Weitzner et. al, 1999). Potential CQOLC scores range from 0 to 104, with higher scores indicating a higher quality of life disturbance (i.e., lower quality of life).

Caregivers in Phase I and Phase II reported nearly identical quality of life scores at the pre-Photovoice time point (d = 0.03) and post-Photovoice time point (d = 0.00).

Additionally, caregivers in both Phase I and Phase II experienced significant improvement in quality of life following their participation in our study procedures. Effect size differences were large for caregivers in Phase I (d = 1.41) and Phase II (d = 0.64).

Please refer to Table 3-8 for these results.

Table 3-8. Effect size differences in spouse/partner caregiver quality of life pre- and post- study participation

<table>
<thead>
<tr>
<th></th>
<th>Pre-Photovoice Mean (SD)</th>
<th>Post-Photovoice Mean (SD)</th>
<th>Effect Size (d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase I Caregivers</td>
<td>46.50 (0.71)</td>
<td>35.00 (15.56)</td>
<td>1.41***</td>
</tr>
<tr>
<td>(N=3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase II Caregivers</td>
<td>46.20 (19.69)</td>
<td>35.00 (15.30)</td>
<td>0.64***</td>
</tr>
<tr>
<td>(N=4)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Note: * = small effect size, ** = medium effect size, *** = large effect size
CHAPTER 4
DISCUSSION

Discussion of Results

The current study is the first to examine the quality of life of individuals impacted by advanced gynecologic malignancies using Photovoice methodology and a mixed methods design. The primary hypothesis prior to initiating study procedures was that the use of Photovoice would elucidate quality of life themes that were informative above and beyond that which has been shown in the current literature. It was also expected that the themes that emerged in Phase I cohorts would differ from Phase II cohorts given the structure of the discussion groups (i.e., dyadic versus patient- or caregiver-only groups). Finally, it was anticipated that the exploratory analyses would reveal improvements in quality of life in patients and spouse/partner caregivers following study participation.

Universal Themes: Cognitive and Emotional Sequelae

Uncertainty

Patients and spouse/partner caregivers impacted by advanced ovarian cancer reported that the cognitive schema most associated with disruption to quality of life was uncertainty. Through their photographs and group discussions, they described that despite the fact that the length of life is unknown to all individuals, an ovarian cancer diagnosis signified limited life expectancy and provided a probable cause of death. Interestingly, this phenomenon has received minimal focus in previous ovarian cancer research. In fact, prior studies have primarily focused on the uncertainty of treatment decision making in women whom have a genetic risk for breast or ovarian cancer (Hurley et al., 2001; Kenen, Shapiro, Friedman, & Coyne, 2007) as opposed to focusing
on women who have been diagnosed with the disease. One prior qualitative study was conducted in which women with recurrent ovarian cancer described the uncertainty associated with “living in limbo,” as they felt they were forced to manage preparing for both life beyond the cancer diagnosis and death (Ekwall, Ternestedt, & Sorbe, 2007). Additionally, female survivors of breast and gynecologic cancers have reported uncertainty to be among the most common stressors following treatment (Lauver, Connelly-Nelson, & Vang, 2007). Higher perception of uncertainty, found to be greater in cancer patients with later stages of disease (i.e., stages II, III, and IV), has also been associated in prior research with higher levels of anxiety pre-and post-surgery in older adults (Lien, Lin, Kuo, & Chen, 2009).

The role of uncertainty in the quality of life of spouse/partner caregivers of ovarian cancer patients has not been addressed in previous published literature, though it has been explored in other cancer populations. In mixed cancer samples, uncertainty in spouse caregivers was among the most profound hospital-based stressors (Vess, Moreland, Schwebel, & Kraut, 1988) and was associated with poorer perceived physical health in spouses (Stetz, 1989). Also, in a recent study, patients who have undergone surgical procedures to treat colorectal cancer and their spouse caregivers indicated in semi-structured interviews that beyond treatment, “Life has a shadow of death” (Ohlsson-Nevo, Andershed, Nilsson, & Anderzen-Carlsson, 2012). Overall, it appears that the results from the present study, including insightful narratives, support the previous literature within the general cancer population and expand upon the limited information regarding the impact of uncertainty on individuals living with advanced ovarian cancer.
**Frustration**

In addition to managing thoughts of uncertainty, patient and spouse/partner caregiver participants reported that feelings of frustration were often present and detrimental to quality of life following the diagnosis of ovarian cancer. The experience of frustration within the context of ovarian cancer has not been discussed in any prior published studies. The use of Photovoice, particularly the shared discussion component within a group setting, likely provided the environment to foster expression of these concerns. In dyadic (Phase I) and patient- or caregiver-only (Phase II) groups, participants were vocal about their frustrations with regard to the ever-present uncertainty and physical limitations secondary to either cancer or spouse/caregiver health concerns. Specifically as it related to uncertainty, frustration was commonly experienced when the “unknowns” of the cancer prognosis/treatment were perceived to dictate the day-to-day lives and future plans of participants. These themes regarding frustration are informative above and beyond any prior published research. Few studies have focused on this particular emotional experience in cancer; however, one study that used interviews and excerpts from diary entries found that frustration was commonly associated with cognitive changes secondary to chemotherapy (e.g., decreased concentration and memory) (Mitchell, 2007). Consequently, although there is a dearth of literature for comparison, it appears that the results regarding the emotional experiences of cancer patients are dependent upon the method of qualitative inquiry.

**Universal Themes: Personal “Survival Techniques”**

**Humor**

Several participants in the present study demonstrated the importance of humor in dealing with the realities of their lives, most frequently regarding patient mortality and
hair loss secondary to chemotherapy. Despite the fact that the use of humor was one of the most commonly observed and discussed coping strategies among patients and spouse/partner caregivers, no published studies to date have explored the role of humor as a coping tool for individuals who are impacted by ovarian cancer. However, humor has been shown in other cancer diagnoses to be not only an effective coping tool in patients and couples, but also a conduit for positive social interaction among cancer support group participants. The use of humor has been negatively associated with levels of distress in women diagnosed with breast cancer (Roussi, Krikeli, Hatzidimitriou, & Koutri, 2007) and positively associated with levels of post-traumatic growth in a general cancer population (Schroevers & Teo, 2008). There is also some suggestion in the literature that Caucasian women with breast cancer are more likely to report using humor-based coping as compared to women who are African American or Hispanic, who tend to rely more on the use religious-based coping (Culver et al., 2004). Within spousal relationships, lower levels of humor usage by the spouse caregiver have been associated with higher levels of distress in lung cancer patients (Taylor et al., 2008) and women with breast cancer have been shown to report lower levels of distress in spousal relationships when the spouse employs humor and self-disclosure during discussion of cancer-related concerns (Manne et al., 2004). As it relates to a group setting, Oliffe and colleagues (2009) demonstrated that the use of humor in a support group for men with prostate cancer served multiple roles including promoting inclusiveness and defusing stoicism within group interactions.

Humor-based coping in individuals impacted by ovarian cancer has likely not been explored for several reasons. First, there is a general paucity of research within
this population. Second, the quantitative focus or individual interview formats that have been used may not allow for this commonly observable coping style to emerge. It is believed that the use of a participant-driven research methodology in a group setting provided the appropriate environment for this coping strategy to be revealed organically and can be further used in the future to better understand the role of humor within an advanced stage ovarian cancer population.

**Faith-based coping**

Themes that emerged through the use of Photovoice procedures regarding the use of faith-based coping were consistent with the current literature within the advanced cancer population. Many participants in this study provided visual and verbal representation of the importance of their faith in the context of the cancer experience, suggesting that this played an integral role in improving their quality of life. Similarly, this was demonstrated in a larger quantitative study by Tarakeshwar and colleagues (2006) in which better quality of life in advanced cancer patients was associated with greater use of positive religious coping (e.g., seeking a stronger connection with a higher power). Although the frequency of faith-based coping in individuals impacted by advanced ovarian cancer has not been explored, one prior study found that family caregivers of ovarian cancer patients reported that use of spiritual or religious faith provided them strength and the ability to find more meaning in their experiences (Ferrell et al., 2002).

**Maintaining personal identity and control**

Women in this study expressed the importance of having a sense of control and continuing to act in accordance with the personal identities that they held prior to being diagnosed with ovarian cancer. They wanted to ensure that their lives consisted of
activities and roles other than those associated with being a cancer patient, discussing ways in which this was achieved throughout their everyday experiences (e.g., continuing to work, exercise, volunteer, and remain engaged in recreational activities to the extent possible). While the ways in which this has been accomplished have not been illustrated in prior research, the existing quantitative literature suggests that ovarian cancer patients who report a greater sense of perceived control also experience fewer symptoms of psychological distress in response to physical impairment and problems with social support (Norton et al., 2005). Therefore, this suggests that perceived control may be a protective factor that lessens the negative impact that difficulties associated with advanced ovarian cancer have on levels of distress. Further, based on participant reports in the present study, it appears that their focus on maintaining personal identity and control provided not only distraction from the cancer experience, but also the independence that they strongly desired. Given the extent of our findings, it is believed that the open-ended, participant-driven format of the Photovoice procedures allowed for the environment in which these themes could be expanded.

Other “survival techniques”

In addition to the use of humor, faith, and maintaining identity/control, participants discussed additional personal coping methods including “sadness diversions” and making preparations for end of life. For patient and spouse/partner caregiver participants, “sadness diversions” entailed activities to distract from the significant time devoted to living with a chronic, poor-prognosis cancer. No prior published studies have explored the role of diversions or distractions used by individuals specifically impacted by advanced ovarian cancer. In addition, existing research on the use of distraction in
female cancers have yielded inconsistent findings. In one study, women who completed
treatment for breast or gynecologic cancers (including, but not limited to, ovarian
cancer) reported that distractions were among the most helpful coping strategies used
(Lauver, Connelly-Nelson, & Vang, 2007). However, in contrast, another study reported
that among patients and family caregivers impacted by advanced breast cancer,
distraction was associated with lower levels of quality of life (Kershaw et al., 2004).
Given the correlational nature of this prior study, one is not able to determine if lower
levels of quality of life were coped with by distraction or if distraction led to lower quality
of life, though qualitative research may provide insight into questions regarding
directionality. While previous studies have yielded conflicting findings regarding the
benefits/detriments associated with distraction as a coping strategy, participants in the
present study remained adamant in their discussions that the use of distractions was
indeed helpful. Specifically, participants indicated anecdotally that distractions or
“sadness diversions” including engagement in hobbies or lighthearted discussions
provided them the opportunity to focus on other aspects of their lives aside from cancer.
Unfortunately, the denial inherently present in a potentially avoidant coping style may
have impacted participants’ perceptions of these benefits as none of the participants
acknowledged any potential detriments associated with this coping style. As a result, it
will be important in future qualitative research efforts to better understand these
relationships through more direct discussion probes (e.g., “Under what circumstances
do you find yourself using distractions most frequently?” or “How do you feel if you are
unable to distract yourself?”).
On the contrary, several patient participants reported quality of life benefits associated with preparing for end of life. The women discussed that given the chronic and incurable nature of their ovarian cancer diagnoses, they wanted assurance that their loved ones would be prepared for their death (e.g., logistical matters including funeral arrangements, distribution of belongings, etc.) and properly cared for beyond their passing (e.g., securing housing for spouse that would otherwise live alone). These themes have not been reported in previous studies of ovarian cancer patients, though similar phenomena were demonstrated in a small qualitative study involving women with metastatic breast cancer (Chunlestskul, Carlson, Koopmans, & Angen, 2008). These authors found that women who actively prepared for end of life reported more life fulfillment and were more at peace with death. Additional qualitative studies have also shown the importance of preparing for end of life in the face of cancer and heart disease in men (Vig & Pearlman, 2003), suggesting that end of life decision making and its associated benefits in chronically ill patients can be best understood through qualitative inquiry. The Photovoice procedures used in the present study were useful in eliciting these themes in an ovarian cancer population and may be of benefit in future studies to further understand the role of preparing for end of life in chronically ill populations.

**Universal Themes: Social Support**

The broad themes that emerged with regard to the importance of social support when living with ovarian cancer were consistent with several previous qualitative research studies. Ferrell and colleagues (2003) provided extensive narratives illustrating the extent to which women with ovarian cancer appreciated and benefitted from the social support that they received. A qualitative, telephone interview-based study revealed that husbands of ovarian cancer patients also rely heavily on receiving support
from loved ones to share the burden of providing support to their wives (Ponto & Barton, 2008). In further support of our findings, prior literature also discusses the positive impact that social support can have on specific aspects of quality of life. In gynecologic cancer survivors, social support has been shown to buffer the negative impact of physical symptoms on patient mood (Carpenter, Fowler, Maxwell, & Andersen, 2010) and in lung cancer patients, less positive social support has been associated with higher levels of psychological distress (Taylor et al., 2008). In summary, results from the present study replicate findings from prior studies in individuals impacted by gynecologic cancers regarding the important role that social support plays in patient and caregiver quality of life.

**Spouse/partner caregiver role and quality of life**

While social support was also found to be valued by spouse/partner caregivers in our study, several men further explained that given the unique role of the spouse/partner caregiver, they oftentimes felt lonely and overwhelmed despite the significant support they received. Spouse/partner caregivers in this sample expressed that their roles were unique given that they were the primary caregivers who were responsible for maintaining constant presence with the patient and managing all other supporters. Their beliefs about this primary role were not unfounded as the patients also described them as being at “the top of the pyramid” or their “foundation.” These themes regarding the unique spouse/partner caregiver role replicate prior findings in which married women diagnosed with breast, endometrial, and ovarian cited their husbands to be the most important member of their support systems (Smith, Redman, Burns, & Sagert, 1985).
Fulfillment of the unique demands associated with the spouse/partner caregiver role appears to be associated with some negative consequences. The results of the present study are consistent with findings from an advanced breast cancer sample in which spouse caregivers reported higher levels of global psychological distress than the patients. In that particular study, this was likely due in part to the fact that while the spouse caregivers and patients reported similar levels of spousal support, caregivers received significantly lower levels of support from family and friends as compared to the patients (Hasson-Ohayon, Goldzweig, Bruan & Galinsky, 2009). Our results suggest that spouse/partner caregivers of women with advanced ovarian cancer endure a similar emotional impact coupled with fewer supportive resources as compared to the patients. In other words, while they reported receiving significant social support from others, they also noted that this did not reconcile the extensive demands placed on them to fulfill the unique spouse/caregiver role nor did they feel that they were provided with equal opportunities to participate in supportive services (e.g., support groups).

**Life Changes in the Context of Ovarian Cancer**

**Relationships**

A consistent theme among participants was the shift in relationships following a diagnosis of ovarian cancer. Some reported that relationships strengthened with spouse/partners, family, and friends. Others discussed that a “filtering” process occurred in which they made efforts to focus more on the quality of their relationships as opposed to the quantity in order to make the most of their time. These themes have not been discussed in prior ovarian cancer research, where the majority of studies focus on relationships and communication in women at risk for ovarian cancer. As compared to a general cancer sample, however, our finding that the experience of cancer encourages
closeness and a strengthening of spouse/partner relationships is consistent with previous studies (Ussher, Tim Wong, & Perz, 2011). No prior published studies have uncovered themes related to cancer patients’ increased discernment for healthy social relationships and their efforts to pursue these experiences. Thus, it is believed that the complexity of relationships, particularly in the context of advanced ovarian cancer, can be best understood using a participant-driven, group format of inquiry such as Photovoice.

**Increased Meaning**

Ovarian cancer patients and their spouse/partner caregivers also reported that day-to-day activities/occurrences held more meaning in the face of cancer. Their discussions regarding increased meaning and appreciation are not unique to the ovarian cancer population. In a prior study in a general cancer sample, appreciation of life was the most commonly reported posttraumatic growth experience (Schroevers & Teo, 2008). As it relates to quality of life, Henry and colleagues (2010) found that the use of a Meaning Making intervention enhanced sense of meaning and improved existential quality of life in women with stage III and stage IV ovarian cancer. Though cause and effect conclusions cannot be drawn, this suggests that women with advanced ovarian cancer who experience greater meaning in their lives also have a better quality of life. While there are fewer studies focusing on life changes in cancer caregivers, a study by Kim, Schultz, and Carver (2007) suggests that family caregivers of cancer survivors also report experiencing an increased sense of meaning and appreciation for life. Using Photovoice, our findings not only confirmed but extended the findings of prior studies given the descriptive narratives discussed among group members. In spouse/partner caregivers especially, our methods fostered discussion
regarding the changed concept of time and how this influenced ways in which caregivers lived their lives.

**Changes to Values and Priorities**

Several women in this study revealed themes of self-improvement in the context of living with ovarian cancer, suggesting that their priorities and values had changed for the better. These discussions commonly occurred with reference to the fact that their struggles facilitated these changes. Similar phenomena have been discovered in women with breast cancer, who have described the concurrent experience of strife and posttraumatic growth (Silva, Moreira, & Canavarro, 2012). Similarly, growth in breast cancer patients has been related to themes including appreciation for life, empowerment, self-perception, and improved interpersonal relationships (Kucukkaya, 2010). Lastly, advanced cancer patients, a sample most consistent with participants in the present study, have reported that perceived impact of cancer was associated with improvements in relating to others, appreciating life, and new possibilities (Mystakidou et al., 2007). Overall, themes in advanced ovarian cancer patients related to personal growth in the context of cancer using Photovoice procedures appear to be consistent with prior research.

**Discourse on Healthcare**

Patients and spouse/partner caregivers impacted by advanced ovarian cancer provided significant insight into their beliefs regarding the healthcare system, the importance of positive interactions with the healthcare team, and the specific characteristics that define a trustworthy healthcare provider. Our findings are consistent with prior studies in which cancer patients and caregivers emphasized the importance of trust in healthcare providers. An interview-based qualitative study revealed that in male
patients with prostate cancer, factors related to the development of trust were most commonly physician expertise and demonstration of compassion (Oliffe & Thorne, 2007). In cervical cancer patients, trust in physicians has been related to both verbal and non-verbal presentations (Brown, Alaszewski, Swift, & Nordin, 2011), similar to participants in the present study who stated that first impressions in healthcare relationships are crucial for these reasons.

In addition to patients, spouse/partner caregivers discussed the importance of their role within the relationship between their wives/partners and the healthcare providers. For caregivers, it was of utmost importance to ensure the quality of the providers and they remained cognizant of this throughout the course of ovarian cancer diagnosis, treatment, and follow-up. Our findings replicate and contribute to the existing literature regarding the caregiver role within the healthcare environment. Gilbert and colleagues (2010) conducted semi-structured interviews with a sample of informal cancer caretakers (including male spouses) to investigate these interactions within the healthcare system. Positive relationships were described with providers who were perceived to be genuine, accepting, accessible, and warm. On the other hand, negative interactions tended to be with providers who were described as lacking empathy and having poor communication skills. Secondary to these negative healthcare interactions were a myriad of distressing emotions including frustration and anger, similar to those which were discussed by participants in the present study.

**Ovarian Cancer-Specific Concerns**

Many of the women in this study expressed their dissatisfaction with the use of the serum CA-125 marker as a clinical tool, primarily due to the fact that CA-125 has a low sensitivity and specificity for ovarian cancer. Patient participants called for more
valid methods of detecting ovarian cancer early, particularly due to the fact that some ovarian cancers are hereditary. In this vein, patient participants contrasted the low sensitivity/specificity of CA-125 for ovarian cancer with the accuracy of breast mammography. Similar themes have emerged in recent qualitative research. In one recent qualitative study, women with ovarian cancer expressed feelings of anxiety and lack of knowledge with regard to the monitoring of CA-125 (Reid, Ercolano, Schwartz, & McCorkle, 2011); however, other qualitative results suggest that the serum CA-125 measurement does not produce anxiety above and beyond other advanced ovarian cancer-related stressors (Jordens et al., 2010). While patients in the present study engaged in some discussion regarding the relationship between CA-125 monitoring and thoughts of uncertainty, they focused more on the ways in which these tests are inadequate and how this related to their advocacy efforts, an aspect of living with ovarian cancer that has not yet been explored in prior studies. While these discussions occurred in both Phase I and Phase II, they were more predominant within patient-only groups (Phase II). In Phase II, the conversations that tended to lead up to patient discussion regarding their frustration with the CA-125 were ones surrounding initial detection of ovarian cancer (i.e., the diagnostic process endured by the patient), suggesting that providing patients with an outlet to discuss these concerns with other similar patients encouraged the exploration of these issues.

**Phase-Dependent Themes**

It was hypothesized that the comparison of dyadic (Phase I) and patient- or caregiver-only (Phase II) discussion groups would yield themes unique to each group condition. This hypothesis was supported in ovarian cancer patients and their spouse/partner caregivers. Most predominantly, this was demonstrated by the diversity
in themes that emerged from patient- or caregiver-only groups. These specific themes are further explored below.

**Burden of Support**

The most prominent and informative phase-dependent theme that emerged was related to ovarian cancer patients’ struggle in managing supportive gestures from others. Women in Phase II, who participated in patient-only discussions, revealed that well-meaning efforts by spouse/partner caregivers, family, and friends had the potential to serve as additional stressors. Further, they revealed that the uncertainty in how to respond graciously to inappropriate or unwarranted advice further exacerbated the difficulties inherent to living with an advanced cancer. The idea that one can be burdened by support has not been explored in any prior ovarian cancer research; however, our results replicate findings from one previous study in a breast cancer population. Reynolds and Perrin (2004) examined wanted and unwanted support in women with breast cancer and found that women reported poorer psychosocial adjustment when they had a mismatch in desired support versus received support. In other words, they had great difficulty adjusting to a breast cancer diagnosis if the support they received was unwanted. Given the nature of this sensitive topic and the fact that it involves spouse/partner caregivers, it is not surprising that ovarian cancer patients in our study expressed these concerns in patient-only groups. Similarly, what also emerged from the discussion was patients’ desire to learn ways of communicating their needs (or lack thereof) to loved ones who provide support.

**Advocacy and Learning to Navigate the System**

Women who participated in Phase II of the study shared themes of both personal and community-level advocacy. Many patients discussed that their experiences within
the healthcare system throughout the course of diagnosis and treatment for ovarian cancer, albeit negative at times, provided them with the motivation to take greater responsibility for their own healthcare. They then shared this healthcare advocacy-related information with loved ones and a small number of women extended this further by promoting advocacy and awareness of ovarian cancer within their local communities. Participants also reported that these efforts of “giving back” contributed positively to the quality of their lives. Advocacy efforts and relationships with quality of life in ovarian cancer patients (and cancer patients in general) have not been addressed in any previous published studies. Therefore, these derived themes are unique to our study, particularly when patient- or caregiver-only discussion groups were conducted (Phase II).

Themes related to navigating the system in spouse/partner caregivers were similar to those in patients regarding personal and community-level advocacy. Caregivers in Phase II described that they experienced a learning process that pertained to the healthcare system in parallel with the patients. While global themes regarding relationships with healthcare providers are discussed earlier in this chapter, exploration of learning about “the system” was unique to men in caregiver-only groups. The men reflected on their roles as advocates for their wives/partners with regard to relationships with providers, treatment decision-making, and financial matters. The themes regarding advocacy and navigating the system likely emerged in these patient- or caregiver-only discussion groups given that the patients and spouse/partner caregivers were able to reflect on issues specifically pertaining to themselves and their own roles as opposed to the couple as a dyad.
Discussion of Fear

The discussion of fear among patient and spouse/partner caregiver participants varied across group formats. In dyadic groups in which patients and caregivers participated together (Phase I), patients expressed their concern and fear for their families following the end of their lives. Similarly, a prior study revealed that women with ovarian cancer reported concern for loved ones to be among the strongest reasons for decreases in quality of life (Houck et al., 1999). On the contrary, caregiver fear of spouse/partner death was not discussed in dyadic groups; rather, it was discussed only in patient- or caregiver-only groups. Though there are no prior studies within the cancer literature to assist in explaining this differential discussion of fear, several possibilities exist. There was some evidence suggesting that male spouse/partner caregivers were uncomfortable with and may have avoided end of life discussions as a small number of men reported that they struggled in finding the “right time” to have these important conversations. Therefore, it is possible that the women in Phase I chose to initiate these conversations regarding end of life and fear for the caregiver in a more moderated group environment to counter any spouse/partner caregiver avoidance. Similarly, caregivers may have reserved their expression of fear for caregiver-only discussions to either reduce the emotional potency without patient presence or to protect the patients from any further burden. Given the chronic and oftentimes terminal nature of advanced ovarian cancer, future research studies should attempt to better understand the barriers to end of life discussions amongst patients and their loved ones.

Frustration with Lack of Attention to Gynecologic Cancers

Patient and spouse/partner caregiver participants in Phase II expressed significant dissatisfaction and frustration with the little support and attention received by
gynecologic cancers as compared to breast cancer. In addition to the differences in diagnostic measures, participants were also frustrated with the lack of political advocacy, education, and supportive services offered to individuals impacted by gynecologic cancers. These themes are similar to those found in a prior qualitative study of women with epithelial ovarian cancer in which patients expressed feeling as though they had a “forgotten cancer” (Power, Brown, & Ritvo, 2008). One hypothesis to explain the emergence of this theme in Phase II is that the cohort sizes were larger in these groups and therefore, may have provided a forum to discuss universal concerns as opposed to individual concerns. Nonetheless, individuals impacted by advanced ovarian cancer appear to be quite distressed by the differential treatment that they feel they receive as a group.

**Participant Commentary**

To summarize, patient and spouse/partner caregivers in Phase I and Phase II expressed that study procedures were not only acceptable, but oftentimes enjoyable and beneficial. The use of photography as a conduit for group interaction and discussion proved to be initially confusing for some participants. Most agreed, however, that the process of deciding on photographs, taking, organizing, and discussing them was helpful in that it forced them to make sense of and relate their experiences with ovarian cancer to others.

**Exploratory Aims**

While participants reported anecdotally that Photovoice participation was beneficial or therapeutic, this study also quantitatively assessed psychosocial functioning pre- and post-study participation. This was achieved through the measurement of mood, patient quality of life, and caregiver quality of life in participants.
across Phase I (dyadic groups) and Phase II (patient- or caregiver-only groups). Our initial hypotheses were that there would be medium effect size differences in patient and caregiver reports of mood and quality of life following study participation. Our hypotheses were partially supported. Patients who participated in Phase I reported a decline in mood and poorer quality of life post-study participation. Quality of life in Phase II patients remained unchanged following participation; however, they endorsed improvements in mood. Among patients, all pre- to post-study changes were small effect sizes. Results in spouse/partner caregivers revealed large effect sizes. Spouse/partner caregivers experienced improvements in mood and in quality of life in both Phase I and Phase II.

It appears that while both group formats are beneficial for spouse/partner caregivers, only patient-only discussion groups are therapeutic for ovarian cancer patients. There are likely several contributors to these findings. First, spouse/partner caregiver reports of negative mood were significant higher pre-study participation as compared to patient participants. This suggests that caregivers may have had a greater need for support initially and had greater room for improvement. Additionally, prior studies have indicated that informal cancer caregivers receive less social support and have access to fewer resources than patients (Ferrell et al., 2002; Hasson-Ohayon, Goldzweig, Bruan & Galinsky, 2009). As a result, caregivers likely experienced improvements in mood and quality of life given that they were provided supportive outlets in both group formats to discuss and reflect on their concerns with others. Indeed, many of the men expressed anecdotally that their discussions in Photovoice sessions were among the first they had regarding these issues.
Regarding the differential response in patients across study phases, results from our small sample suggest that women both prefer and report greater outcomes when they engage in group discussion with other women who have had similar experiences. Indeed, a previous study examining support group participation in women with ovarian cancer found that they felt it most important to share information, engage in reciprocal emotional support, and to “be in the same boat” with other participants (Ahlberg & Nordner, 2006).

It is important to note that these quantitative results are only tentatively offered, as the present study did not use an experimental design, and therefore it cannot be inferred that Photovoice elicited these improvements. However, these results suggest that it may be fruitful to examine Photovoice as a method for improving mood and quality of life using an experimental design and patient- or caregiver-only discussion groups.

**Implications of Findings**

The present study is the first to examine quality of life themes in individuals impacted by advanced gynecologic malignancies using Photovoice, a participant-driven form of inquiry in a group setting. Our findings indicate that the use of Photovoice as a tool to qualitatively measure quality of life can not only be used to confirm and expand upon existing literature, but also to elucidate novel themes above and beyond that which has been shown in previous studies. In summary, our methods uncovered themes regarding participant cognitive and emotional sequelae, coping strategies used, life changes in the context of cancer, and specific concerns regarding ovarian cancer and healthcare. Photovoice methods provided a balanced assessment of the needs and assets of this population. Given its ability to determine the themes most salient to
participants, future research focusing on these areas may be able to provide further insight into the effectiveness of reported coping methods and quantify the extent of life changes in the face of ovarian cancer. The findings also served to shape future directions for the psychosocial treatment of individuals living with ovarian cancer. For example, the results pertaining to the frequency of uncertainty and frustration in individuals provides implications for cognitive behavioral intervention.

The present study was also the first to compare and contrast the themes that emerged through Photovoice participation in dyadic versus patient- or caregiver-only groups. Completing the study in two phases, allowed for the ability to explore which format may elicit the most novel and elaborative themes and yield the most beneficial effects on mood and quality of life.

While many of the themes were global and occurred across both conditions, a greater diversity of themes was found when participants were in patient- or caregiver-only groups. Results suggested that ovarian cancer patients were more likely to reflect on the burden of support and their increased personal advocacy efforts among discussions with other women. On the other hand, it appeared that spouse/partner caregivers reserved expressions of their fear and navigating the healthcare system as a caregiver to conversations within caregiver groups. In order to best meet the needs of group participants, future research endeavors should aim to understand how relationships among group members can predict the content of discussion and its quality of life impact. It would also be interesting to explore the reasons underlying the emergence of more diverse themes in patient- or caregiver-only groups, as this would inform the mechanisms by which individuals impacted by ovarian cancer are able to
elaborate upon and process their concerns. For instance, it is unclear whether groups should be comprised of participants of the same gender or participants fulfilling the same roles, irrespective of gender. As ovarian cancer only occurs among women, and all of our participants were in heterosexual relationships, all of our participants were female and all of our spouse/partners were male. In cancer diagnoses not related to the reproductive organs, this would not be the case; therefore, for these cancers, it would be important to understand the characteristics on which group members identify and relate the most (i.e., role versus gender).

Lastly, the present study was the first to examine the potential for Photovoice to be an intervention tool within a cancer population, specifically in individuals impacted by advanced ovarian cancer. The results suggested that Photovoice is beneficial for spouse/partner caregivers regardless of group format and for ovarian cancer patients in patient-only groups. Based on these findings, it appears that group interventions are generally less beneficial and informative when ovarian cancer patients and caregivers participate simultaneously. However, these results are based on a small sample size and without an experimental design. Future research in larger samples is necessary as it will provide sufficient statistical power to conduct further analyses. If further studies indicate that role-specific groups are most beneficial, then it is recommended that the standards of cancer care be modified accordingly to provide supportive environments that meet the needs of all participants.

**Study Limitations**

Despite the informative findings as previously discussed, the results of this study should be interpreted with caution given several important limitations. First, the entire sample was comprised of only Caucasian participants. While ovarian cancer is more
common in Caucasian women (American Cancer Society, 2009), the results cannot be
generalized to individuals impacted by poor prognosis ovarian cancer of other racial or
ethnic backgrounds. Findings from a prior Photovoice study among African American
women with breast cancer suggest that quality of life concerns are primarily driven by
factors related to minority status including the experience of discrimination by
healthcare providers and stigmatizing beliefs about breast cancer within minority
communities (Lopez, Eng, Randall-David, & Robinson, 2005). Therefore, it cannot be
assumed that the experience of individuals impacted by advanced ovarian cancer who
are not Caucasian would mirror the themes from the present study. In order to bridge
this gap, future studies would benefit from increased efforts to recruit and retain a more
racial and ethnically diverse sample of participants to best understand their unique
experiences.

Second, the number of study sessions completed by participants in Phase I
versus Phase II varied greatly. In general, participants in Phase I completed only the
Photovoice Training Session and first Photo-Discussion Session; whereas participants
in Phase II completed the Training Session, two Photo-Discussion Sessions, and the
Findings and Feedback Session. As a result, it is possible that the findings were
impacted by the variations in exposure to Photovoice study procedures, opportunities
for group discussion, and the development of trust among group members that may
have evolved over the course of multiple sessions. Attrition was a large barrier to
maintaining consistent participation. As the study reached its midway point, an
evaluation of factors contributing to attrition was conducted, and procedures were
adjusted accordingly. The most helpful adjustment made was to conduct study sessions
closer to the homes of participants. This significantly improved attrition rates; therefore, continuing the practice of accommodating participant needs is recommended in future studies as it is consistent with the mission of Community Based Participatory Research (Agency for Healthcare Research and Quality, 2009).

Similarly, the size of cohorts across Phase I and Phase II varied greatly, with a greater number of patients and spouse/partner caregivers participating in Phase II cohorts. This likely resulted from the aforementioned improvements in retention efforts. Although it has been attributed to group format, it is possible that the diversity of themes that emerged in Phase II sessions was due in part to the increased number of participants within these sessions. In order to control for cohort size, future research would benefit from extended recruitment time to allow for complete and equally sized cohorts to form prior to initiation of study procedures.

Lastly, despite the fact that qualitative studies involving multiple group meetings commonly consist of small sample sizes, our sample of nine couples is a limitation. Unfortunately, this limitation was further exacerbated by forming two separate groups for comparison, leaving four and five couples in each condition, respectively. However, the total number of participants within each condition remains comparable to a prior published Photovoice study involving dyads within the cancer population (Yi & Zebrack, 2010). Nonetheless, there was not sufficient power to test for statistical significance. While the quantitative results are promising, including many large effect size differences, it is not possible to determine if these findings were statistically significant. Future research using Photovoice would benefit from recruiting larger samples and
conducting these using a randomized controlled trial design to further understand outcomes pre- and post-Photovoice participation.

**Conclusions**

The present study was the first to examine the quality of life of individuals impacted by advanced gynecologic malignancies using Photovoice. To understand the role of spouse/partner presence within these Photovoice sessions, this study was also the first to make comparisons between the themes that emerged in dyadic versus patient- or caregiver-only groups. The results replicate and expand upon findings in prior literature by increasing the understanding of the experiences of individuals impacted by poor-prognosis ovarian cancer. Specifically, the present study was among the first to explain the ways in which couples living with ovarian cancer experience uncertainty, frustration, life changes in the context of cancer, and difficulties within the healthcare system. Knowledge was also further increased regarding their coping strategies, or “survival techniques,” including use of social support, humor, religious/spiritual faith, and maintaining personal identity and control. In addition to these universal themes, when women participated in discussions among other ovarian cancer patients, they were more likely to diversify their conversations to include additional concerns. Most notably, they provided significant insight into ways in which support from others can be burdensome or distressing.

Participants qualitatively reported that they enjoyed their involvement in Photovoice sessions and generally found the group meetings to be therapeutic. The investigation of our exploratory aims provided evidence that Photovoice has the potential to improve mood and quality of life and that it can be used as an intervention tool within this population, with some caveats. To maximize the benefit for both patients
and spouse/partner caregivers, Photovoice groups should be held separately so that the individuals within each couple can participate in environments that foster openness and camaraderie.

To conclude, the present study highlights the experiences, needs, and assets of an understudied population of ovarian cancer patients and their spouse/partner caregivers. Given the lack of research within this population, the findings offer insight into the areas of utmost importance to individuals living with ovarian cancer, providing cues for future research directions. Findings also suggest that Photovoice can be used as both measurement and intervention tools within this population.
LIST OF REFERENCES


Derogatis L.R. & Spencer P.M. *The Brief Symptom Inventory: Administration, Scoring and Procedures Manual*. Johns Hopkins University School of Medicine, Clinical Psychometrics Research Unit: Baltimore, MD, 1982.


Hurley, K.E., Miller, S.M., Costalas, J.W., Gillespie, D.D., & Daly, M.B. Anxiety/uncertainty reduction as a motivation for interest in prophylactic oophorectomy in women with a family history of ovarian cancer. *Journal of Women’s Health & Gender-Based Medicine, 10*(2), 189-199.


BIOGRAPHICAL SKETCH

Megan Lipe Armstrong was born in 1985 in Fayetteville, North Carolina. She graduated magna cum laude from Louisiana State University in 2007, receiving a Bachelor of Science degree in Psychology. During her time at Louisiana State University, she worked as a research assistant in a laboratory investigating the psychological impact of Hurricane Katrina on school-aged children in Louisiana and was a research assistant in the Women's Health, Smoking Cessation, and Eating Behaviors laboratory at Pennington Biomedical Research Center in Baton Rouge, Louisiana. She also worked as a school shadow for a child with autism, implementing Applied Behavioral Analysis protocol.

Megan began attending graduate school at the University of Florida in the Department of Clinical and Health Psychology in August 2007. Megan focused her research in the area of behavioral medicine and received her Master of Science degree in 2009. Her master’s thesis was entitled, “A Risk and Resistance Model for Predicting Medication Adherence in Young Children with Asthma: Role of Parent Stress, Child Temperament, and Social Support.” In 2007 and 2008, she received two research mini-grants from the University of Florida Center for Pediatric Psychology and Family Studies to fund her master’s project. In 2009, she received the College of Public Health and Health Professions Outstanding Research Award.

Under the mentorship of Deidre B. Pereira, Ph.D., Megan further focused her research on the area of Psycho-Oncology and women’s health. She served multiple roles within this research laboratory including co-authoring a cognitive behavioral intervention manual for insomnia, pain, and mood difficulties secondary to cancer for the NCI-funded R01 study entitled, “Cognitive Behavioral Effects on Sleep, Pain, and
Cytokines in Gynecologic Cancer.” She was also very involved in community service and was awarded the Department of Clinical and Health Psychology’s Jenny Sivinski Award for Excellence in Community Service.

In June 2012, Megan completed a one year pre-doctoral internship at Tulane University in New Orleans, Louisiana. Megan is currently a volunteer for the Louisiana/Mississippi Chapter of the Leukemia Lymphoma Society and serves as a member on the Tulane Arts in Medicine Community Advisory Board. In July 2012, Megan accepted a two year postdoctoral fellowship at Louisiana State University Health Sciences Center in the Department of Physiology. Megan will begin this fellowship upon completion of her doctoral degree and will focus her efforts on developing and implementing interventions to decrease alcohol use in individuals with HIV/AIDS.