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College of Humanities and Sciences
Virginia Commonwealth University

This is to certify that the dissertation prepared by HaNa Kim entitled
Understanding Death Anxiety in Women with Gynecologic Cancer has been
approved by her committee as satisfactory completion of the dissertation requirement for
the degree of Doctor of Philosophy.

Kathleen M. Ingram, J.D., Ph.D., Director of Dissertation, Department of Psychology

Cecelia H. Boardman, M.D., Department of Obstetrics and Gynecology

Jeffrey D. Green, Ph.D., Department of Psychology

Timothy L. Hulsey, Ph.D., Department of Psychology and The Honors College

Pamela J. Kovacs, Ph.D., School of Social Work

Robin K. Matsuyama, Ph.D., Department of Social and Behavioral Health

Wendy L. Kliewer, Ph.D., Director of Graduate Studies

Frederick M. Hawkrigde, Ph.D., Interim Dean, College of Humanities and Sciences

F. Douglas Boudinot, Ph.D., Dean, School of Graduate Studies

Date

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UNDERSTANDING DEATH ANXIETY IN WOMEN WITH GYNECOLOGIC
CANCER

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

by

HANA KIM

Master of Science, Virginia Commonwealth University, 2007
Bachelor of Science, University of Florida, 2004

Director: Kathleen M. Ingram, J.D., Ph.D.
Associate Professor of Psychology
Department of Psychology

Virginia Commonwealth University
Richmond, Virginia
May, 2010

Dedication

To Mom, Dad, and Du Na, who mean the world to me

and

To the 10 extraordinary women who were willing to spend an hour of their time to help actualize this study. Thank you for your invaluable contributions.

Acknowledgments

I would like to express my deepest thanks to my chair, Dr. Kathleen Ingram, and committee members, Drs. Cecelia Boardman, Jeffrey Green, Timothy Hulsey, Pamela Kovacs, and Robin Matsuyama for their support, encouragement, and feedback during the dissertation process. I would also like to thank my auditors, Jessye Cohen and Karen Kersting, for their time, thorough readings of my transcripts, and insightful comments. And my gratitude goes out to Jane Baggett, Bonnie Epperson, and Marcia Megginson, the nurses at Massey who made participant recruitment both an enjoyable and successful process. All of you have contributed immensely in helping me create such a personally meaningful project.

There are two individuals I wish to especially thank because of the significant influence they have had on my graduate school training. First, I would like to thank Dr. Kathy Ingram, my academic advisor, for allowing me to be an independent and creative thinker in an often very structured academic environment. Kathy's open approach to advising has allowed me to explore many interesting and exciting opportunities as a student. On a personal level, I appreciate the characteristics and values that Kathy embodies and admire her humor, warmth, and kindness. I feel very fortunate to have had someone like her as my advisor. Second, I wish to thank Dr. Tim Hulsey, my informal mentor for the past several years. Tim agreed to meet with me on an individual basis for an independent reading study, a way for me to increase my knowledge in clinical theory. His expectations were simple: think, be curious, and ask questions. Yet, what I have learned from him has been far from simple and more valuable than anything I have gained in a classroom setting. My interactions with Kathy and Tim have often inspired me to reflect and refocus the direction of my training. And for that, I am grateful to the both of them.

I would also like to acknowledge my classmates: Wendy Balliet, Monica Durette, Becky Foster, Remy Jones, Andrea Miller, Sara Trace, Nile Wagley, and the late Juana Wu. The support they have given me throughout our years in Richmond is something I cannot put into words. Last, I would like to thank my parents and little brother for cheering me on through the highs and lows and, most importantly, for providing humor.

Table of Contents

| | Page |
|---|------|
| Dedication | ii |
| Acknowledgements | iii |
| List of Tables..... | vii |
| List of Figures | viii |
| Abstract | ix |
| Chapter | |
| 1 Introduction..... | 1 |
| Understanding Death Anxiety | 5 |
| 2 Literature Review..... | 8 |
| Gynecologic Cancer..... | 8 |
| Gynecologic Cancer and Psychosocial Issues | 13 |
| The Problem of Death..... | 26 |
| Terror Management Theory..... | 30 |
| Intersection of Terror Management Theory and Cancer | 37 |
| Qualitative Research..... | 48 |
| Philosophical Paradigms..... | 50 |
| Grounded Theory..... | 53 |
| Research Question | 55 |
| 3 Method | 57 |
| Research Design | 57 |

| | |
|--|-----|
| Role of the Researcher..... | 58 |
| Participants | 58 |
| Data Collection Procedures | 59 |
| Data Analysis..... | 64 |
| Threats to Trustworthiness | 68 |
| Summary..... | 71 |
| 4 Study Findings | 72 |
| Description of Sample | 72 |
| Participant Summaries..... | 73 |
| Description of Findings | 77 |
| Cancer as a Reminder of Mortality..... | 77 |
| Self-preservation..... | 80 |
| Managing Awareness of One’s Own Mortality..... | 84 |
| Dignity Overrides Self-preservation..... | 100 |
| Integration of Cancer into Life | 102 |
| 5 Discussion | 106 |
| Reflections During the Study..... | 106 |
| Limitations..... | 112 |
| Summary..... | 114 |
| Relation to Previous Research Findings..... | 118 |
| Implications for Theory | 122 |
| Implications for Research..... | 128 |

| | |
|-------------------------------------|-----|
| Implications for Practice..... | 132 |
| Conclusion | 136 |
| Final Thoughts..... | 138 |
| References | 145 |
| Appendices | 156 |
| A Demographic Questionnaire..... | 156 |
| B Participant Consent Form..... | 160 |
| C Interview Guide..... | 165 |
| D Phone Script | 168 |
| E Audit Trail..... | 170 |
| F Interview Questions..... | 172 |
| Vita..... | 181 |

List of Tables

| | Page |
|---|------|
| Table 1: Selected Demographic Characteristics of Participants. | 140 |
| Table 2: Categories and Subcategories | 141 |
| Table 3: Participants within Each Category and Subcategory | 143 |

List of Figures

| | Page |
|--|------|
| Figure 1: Model of Managing Death Anxiety..... | 144 |

Abstract

UNDERSTANDING DEATH ANXIETY IN WOMEN WITH GYNECOLOGIC CANCER

By HaNa Kim, M.S.

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

Virginia Commonwealth University, 2010

Director: Kathleen M. Ingram, J.D., Ph.D.
Associate Professor of Psychology
Department of Psychology

For most of us, thoughts about our own mortality are largely unconscious, an invisible backdrop to our daily living. However, when forced to face a potentially life threatening event, these otherwise underlying thoughts about human transience rise to consciousness. Given the seemingly inherent link between receiving a cancer diagnosis and developing an increased awareness of one's own mortality, the present study sought to address the following research question, "What are the experiences and processes by which women with gynecologic cancer construct meaning and manage death anxiety in the face of their cancer diagnosis?" Based on an interpretive grounded theory paradigm, 10 women with gynecologic cancer were interviewed to gather rich, nuanced information about the phenomenology of death anxiety in this understudied cancer population.

The primary ways in which participants managed the threat of mortality were to engage in certain socially-sanctioned behaviors related to religion, spirituality, family, identity, and social obligations. These activities served a dual purpose by (1) giving participants the opportunity to fight symbolically or literally against death and (2) allowing them to derive a sense of meaning and purpose in life. Findings from this study offer a unique conceptual understanding of the cancer experience. Implications for theory, research, and practice are discussed.

CHAPTER ONE

Introduction

The irony of man's condition is that the deepest need is to be free of the anxiety of death and annihilation; but it is life itself which awakens it, and so we must shrink from being fully alive.

—Roy D. Waldman

The word *cancer* originated from the Greek physician Hippocrates (460-370 B.C.). To describe the long jutting shapes emanating from a cancerous tumor, he employed the words *carcinosis* and *carcinoma*, ancient Greek terms that refer to crabs (American Cancer Society [ACS], 2002). Historical evidence reveals that cancer, a once incurable disease, has threatened against humans since at least 1600 B.C. (ACS, 2002). Unfortunately, the magnitude of this threat has not decreased. In 2009, cancer will claim the lives of over half a million individuals in the United States alone (ACS, 2009). This translates into approximately 1,500 people per day. Further, a staggering 1,479,350 people in the U.S. will be newly diagnosed with cancer in that same year (ACS, 2009).

Despite modern technological advances in medicine and the relatively high survival rates for certain diseases, humans have never been without the fear of death. Individuals given a cancer diagnosis, regardless of prognosis, are faced with the reality that their very being has been compromised, perhaps fatally. Because thoughts about our own mortality are generally suppressed and largely unconscious, a cancer diagnosis is a rude reminder that we are mortal and that our bodies are susceptible to death, no more or

less than any other animal. Death remains a taboo subject, particularly in this country where we have euphemisms for dying such as “resting,” “sleeping,” “gone to heaven,” and “in a better place now.” Though the scholarly literature on death has increased in the past 40 years, most of these studies revolve around palliative care, hospice, or terminally ill patients.

Much of the resistance to discussing death is related to the underlying fear of dying. As Elisabeth Kübler-Ross (1969) noted, the fear of death is a universal fear. After all, no one is exempt from death. She wrote, “Man has to defend himself psychologically in many ways against this increased fear of death and increased inability to foresee and protect himself against it” (p. 12), because “...in our unconscious mind, we are all immortal” (p. 37). She notes that the use of nuclear bombs and modern weaponry designed to kill hundreds of people at once and at a distance is an indication that we have difficulty accepting death with dignity.

The natural reaction for most people is to deny death. Denial is a powerful psychological mechanism, often necessary in the face of trauma to preserve the self (Jones, 1999). The fluidity of denial is pervasive, allowing it to shift and change. For those with cancer, denial is not fixed at diagnosis. Rather, it moves in and out of the patient’s experience across time, granting the patient freedom to go about living in its presence. The initial denial is substituted with partial acceptance, and then replaced by anger and rage after the news has settled in (Kübler-Ross, 1969). Cancer patients look at those around them: nurses, doctors, custodial workers, effortlessly using their legs to

walk quickly down the hallways, moving deftly down the stairs to return to the comforts of home, and all the while the sick patient cannot even get out of bed.

Bargaining is the third stage. Here, patients cling to the hope that good behavior will be rewarded with an extension of life. Kübler-Ross (1969) compares this with the child who stamps her foot and gets angry after being told she cannot play with her friend, but then later asks her parents if she can play with the friend in exchange for washing the dishes.

As terminally ill patients grow sicker and weaker, and are beset by increasing financial burdens, depression sets in. This is the fourth stage (Kübler-Ross, 1969). The fifth stage is acceptance. The patient has had time to process and work through the previous feelings of shock, anger, and depression. This should not be mistaken for happiness, but rather peace. The individual tends to sleep more, is devoid of feelings, and requests shorter and fewer visits from family and friends. Nonverbal actions, such as sitting quietly in silence replaces verbal language. This is the final stage before death (Kübler-Ross). Although these stages are described in a linear fashion, terminally ill individuals face death in various ways depending on age, culture, type of illness, and a host of other underlying factors.

A common thread that links these fluid stages is the idea of hope: something unforeseeable might happen that could extend life. The cancer might go into remission. A new drug therapy might be invented. Those whose death was imminent clung on to a small thread of hope that Kübler-Ross described as “nourishing” (1969).

For the cancer patient, the most salient psychological feature of a cancer diagnosis is the fear of dying (Kübler-Ross, 1969). Yet, the majority of studies related to sickness and disease examine “easily accessible variables such as sex, age, and religion” (Cella & Tross, 1987, p. 451). Studies that have examined death anxiety in cancer patients have yielded interesting findings about the nature of death anxiety as well as how different types of patients manage this anxiety.

The concept of death anxiety, although seemingly abstract, has been measured with moderate reliability and validity. Generated from qualitative findings, the Death Anxiety Scale (Conte, Bakur-Weiner, & Plutchik, 1982) examines thoughts and fears about death and dying such as worries about a painful death, not being remembered after dying, and being a burden to loved ones during the dying process. Studies using this scale have found no significant differences in death anxiety scores between cancer patients in early (I and II) or late (III and IV) disease stages (Cella and Tross, 1987; Sigal et al., 2008). Patients greater than 5 years post diagnosis and treatment had statistically significant lower scores than patients within 2 years of their diagnosis, suggesting that the effects of death anxiety may be a function of the amount of time living with the disease, rather than cancer stage or type (Cella & Tross). The one exception is terminally ill patients who report greater psychological distress (Sigal et al.).

Coyle and Sculco (2004) conducted a qualitative inquiry of the expressed desire for hastened death in a mixed cancer sample. All patients were in the advanced stages of the disease. Interviews revealed that the participants expressed a desire for hastened death for several reasons, including perceived loss of social support; progressive

worsening of disease; loss of dignity, autonomy, and self worth; loss of sense of purpose in the world; and feeling like a burden to self and others. More acute reasons for desiring hastened death were pain, shortness of breath, hopelessness, sense of dread, and receiving medically-related information that evoked fear.

These findings illuminate the complexity of cancer patients' experiences, particularly with regard to end-of-life issues. The paradoxical nature of wanting to live yet end the psychological and physical pain underscores the very human nature of living with a life threatening illness.

A number of studies using healthy samples have found that, in general, women report higher death anxiety than men (e.g., Mosher & Danoff-Burg, 2007; Thorson & Powell, 1988). Cross-cultural comparisons have also found similar evidence for this gender difference (Lester, Templer, & Abdel-Khalek, 2006-2007). The relation between death anxiety and age is not clear, although several studies conducted in the early 1960s consistently demonstrated that older individuals show less fear of death versus younger ones (for a review see Lester, 1967).

Understanding Death Anxiety

In a relatively new area of empirical research, investigators have applied Terror Management Theory (TMT; Koole, Greenberg, & Pyszczynski, 2006; Pyszczynski, Solomon, & Greenberg, 2003) to understanding death anxiety. Based on the work of Ernest Becker (1973), TMT posits that managing the anxiety created by awareness of mortality is humans' core psychological struggle. The principal method for managing this anxiety is investing emotionally and psychologically in culturally shared belief

systems (e.g., religion, patriotism, social organizations), which give life meaning while concurrently enhancing individual self-esteem (Pyszczynski et al., 2003). By investing in shared worldviews, humans seek to gain approval from their social group and the self-esteem that arises from a sense of belonging.

Over 200 TMT studies (Koole et al., 2006) have found empirical support for the claim that participating in certain socially-sanctioned behaviors serves to restore psychological equanimity after reminders of mortality. These studies have found evidence that social support (e.g., Arndt, Greenberg, Schimel, Pyszczynski, & Solomon, 2002), religion (e.g., Greenberg et al., 1990), and culture (e.g., Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon, 1989) all serve to manage the anxiety produced by the explicit awareness of mortality.

Though TMT has been widely studied, few of these studies have utilized qualitative approaches. Fewer still have examined death anxiety in medical populations, such as individuals diagnosed with cancer. The present researcher has chosen to address these gaps by utilizing a qualitative methodology and a medical population. To that end, women diagnosed with gynecologic cancer were recruited, a group largely overlooked in the cancer literature. The research question was “What are the experiences and processes by which women with gynecologic cancer construct meaning and manage death anxiety in the face of their cancer diagnosis?” The goal was to identify themes and patterns in the women’s descriptions of their concerns about death and dying and how they manage this anxiety.

In what follows, the ideas mentioned in this Introduction will be explained and elaborated upon in further detail. In Chapter Two, an overview of the literature on gynecologic cancers will be given. Following this will be a review of both the research examining the psychological implications of gynecologic cancer and the TMT literature on death anxiety related to illness, and then the basis for the fusion of these two research areas. Since a grounded theory approach (Charmaz, 2006; Strauss & Corbin, 1990) was utilized for methodological purposes, an overview of qualitative research as well as the rationale for using a qualitative approach to explore the research question will be provided. Chapter Three contains detailed information about the participants, recruitment procedures, data collection method, and study limitations. In Chapter Four, the findings from the present study will be outlined. Lastly, the implications for research, theory, and practice will be discussed.

CHAPTER TWO

Literature Review

Gynecologic Cancer

Endometrial cancer. Approximately 80,720 new cases of gynecologic cancers are diagnosed in the United States every year, including cancers of the uterine corpus, uterine cervix, ovaries, and vagina (ACS, 2009). The most common gynecologic malignancy in the U.S. is endometrial cancer with an estimated lifetime risk of 1 in 41 (ACS, 2008).

The uterus is a hollow, pear-shaped organ divided into the cervix (lower portion of the uterus) and the corpus (upper portion). Endometrial cancer stems from malignancy of the innermost lining of the uterus, the endometrium. An estimated 42,160 women in the U.S. will be diagnosed with endometrial cancer in 2009 and 7,780 of those affected will die (ACS, 2009).

Although endometrial cancer is more commonly diagnosed in Caucasian women than their African American counterparts, African American women have a higher mortality rate (ACS, 2009). More than 50% of all endometrial cancer cases are found in women between 55 and 74 years of age, with most cases seen in women over the age of 55 (ACS, 2008). The American Cancer Society (2009) shows a relative 5-year survival rate of 83% for all endometrial cancer stages combined and a 96% relative 5-year survival rate for early stages only (Stage I). Among endometrial carcinomas in the

United States, up to 80% consist of typical adenocarcinomas or cancer of the glandular cells of the endometrium (ACS, 2008).

Research has shown a link between endometrial cancer and estrogen therapy. High levels of unopposed estrogen increase the risk of developing endometrial cancer, although there is also evidence that endometrial cancer growth may be prevented through progestins (ACS, 2009). Additional factors for endometrial cancer risk are tamoxifen (a selective estrogen receptor modulator prescribed for breast cancer treatment or reducing breast cancer risk), obesity, early menarche, and late menopause (ACS). Research shows that potential prevention methods include taking oral contraceptives, maintaining a healthy diet, and exercise. Treatments for endometrial cancer are surgery (the most common method), radiation therapy, hormonal therapy, chemotherapy, or a combination of these of treatments (ACS).

Ovarian cancer. Ovarian cancer is the second most common gynecologic malignancy in the United States (ACS, 2009). This cancer ranks fifth among all cancer deaths in women, excluding non-melanoma skin cancers (ACS, 2008). Cancer begins in the ovaries, the female sex glands that produce eggs, which contain three different types of tissue: germ, stromal, and epithelial. The most common type of ovarian cancer occurs in the epithelial cells, the outermost layer of the ovaries. Many types of ovarian tumors exist, including epithelial ovarian tumors, primary peritoneal carcinomas, and germ cell tumors. The lifetime risk for an invasive ovarian cancer diagnosis is approximately 1 in 71; the lifetime chance of dying from such a diagnosis is about 1 in 95, excluding non-malignant ovarian tumors (ACS, 2008).

It is estimated that around 21,550 U.S. women in the year 2009 will be newly diagnosed with ovarian cancer and nearly 14,600 women will die (ACS, 2009). Most ovarian cancer cases are diagnosed in women aged 55 years or older and also diagnosed slightly more frequently in Caucasian women than African American women. The 5-year survival rate for women diagnosed with ovarian cancer is 46% (ACS), considerably lower than the survival rate for other gynecologic cancers. Diagnosis and treatment of ovarian cancer before it has spread outside of the ovary boosts the 5-year survival rate to 93%, although only 19% of all ovarian cancers are found at this early stage (ACS). Low detection in early stages may be due to lack of screening measures for ovarian cancer, unlike mammograms and Pap tests for breast cancer and cervical cancer, respectively. In addition, mild symptoms such as fatigue and urinary difficulties exhibited by women in an early disease stage may fail to prompt women to seek medical services or may be overlooked by clinicians (Smith & Anderson, 1985). Common physical symptoms in late stage disease include pain and abdominal distension. Women experiencing such symptoms tend to seek medical treatment in the presence of irregular menses or pain (Ferrell, Smith, Cullinane, & Melancon, 2003; Smith & Anderson).

Inherited genetic factors such as mutated BRCA1 and BRCA2 genes, generally thought of as potential causes of breast cancer, account for a portion of lifetime ovarian cancer risk in women (ACS, 2008). The lifetime risk in women carrying a mutation of the BRCA1 gene is estimated to be 35% to 70% whereas for women with a BRCA2 mutation, the lifetime risk is between 10% and 30% by 70 years of age (ACS, 2008). Carriers of a mutated gene have the option of a prophylactic oophorectomy as a way to

prevent ovarian cancer. Other risk factors include older age, obesity, family history of breast or ovarian cancer, and estrogen-only hormone therapy (ACS, 2009). Risk reduction methods include oral contraceptives, pregnancy, and preventive surgery to remove the ovaries. Main treatment modalities are chemotherapy, radiation therapy, and surgery (ACS, 2009).

Cervical cancer. A slow growing tumor that begins in the lining of the cervix, the lower portion of the uterus, is known as cervical cancer. Although this cancer is not as common as endometrial or ovarian cancer, it has received recent attention because of its strong association with particular strains of genital human papillomavirus (HPV; see Koutsky, 1997), a sexually transmitted disease.

Classification of cervical cancers is made by examining cells at microscopic levels. Approximately 80% to 90% of cervical cancers develop from the squamous cells that cover the endocervix (part of the cervix closest to the uterus) with the majority of cancers beginning in the endocervix and ectocervix (part of the cervix closest to the vagina) junction (ACS, 2008). Cervical cancers of this origin are called squamous cell carcinomas. The remaining 10% to 20% of cervical cancers are considered adenocarcinomas or cancer of the endocervical gland cells (ACS). Only some women with precancerous changes in the cervix will develop cancer (ACS).

Around 11,270 women in the U.S. will be diagnosed with invasive cervical cancer in 2009 with an estimated 4,070 deaths (ACS, 2009). In the last few decades, mortality rates for cervical cancer have steadily declined because of the advent of screening measures such the Pap test, a device used to detect abnormal cell changes in the cervix

(ACS, 2009; Devesa, Silverman, & Young, 1987). Cervical cancer is diagnosed most often in Hispanic women with the rate of diagnosis being twice that of their non-Hispanic Caucasian counterparts (ACS, 2008). Further, African American women are diagnosed with cervical cancer 50% more frequently than non-Hispanic Caucasian women (ACS, 2008). Unlike ovarian and endometrial cancer, cervical cancer tends to occur in younger women under the age of 50; 20% of women with this disease are diagnosed over the age of 65 (ACS, 2008). The 5-year survival rate for localized cervical cancer is 92%, whereas the rate for all stages combined is 88% (ACS, 2009).

Risk factors for cervical cancer include chlamydia infection, multiple pregnancies, family history of cervical cancer, lower socioeconomic status (SES), oral contraceptives, cigarette smoking, and most notably HPV (ACS, 2008). It is estimated that two thirds of all cervical cancer cases are caused by “high risk” types of HPV, specifically virus types 16 and 18 (ACS). Due to the sexual nature of acquiring HPV, such a diagnosis elicits feelings of being stigmatized for some women. A qualitative study of 52 women, recently diagnosed with HPV after a routine Pap test, revealed five main emotional reactions: stigma, fear, self-blame, powerlessness, and anger (Perrin et al., 2006). Semi-structured, in-depth interviews were designed to understand women’s initial reactions to their diagnosis. Stigma of acquiring a sexually transmitted disease was the most frequently cited reaction among the participants. Women also reported feeling fearful at the thought of developing cancer, anger at their sexual partners, self-blame for making poor sexual choices, and powerlessness in not knowing where they acquired the virus (Perrin et al.).

The recent development of a vaccine to prevent young girls from being infected with certain strains of HPV in the future has catapulted cervical cancer into the media spotlight because of the association of genital HPV as a sexually transmitted disease (see Slomovitz et al., 2006). Despite moral debates surrounding the vaccine, this prevention tool in combination with Pap tests makes cervical cancer a highly preventable disease. Surgery, chemotherapy, and radiation therapy are standard medical treatment procedures for cervical cancer (ACS, 2009).

Gynecologic Cancer and Psychosocial Issues

Sexuality. Sexual issues are a major concern for women diagnosed with gynecologic malignancies. Given that the very nature of the disease may require invasive treatment procedures to the female reproductive system, this concern is not surprising. Women have reported experiencing orgasm difficulties (Laganà et al., 2005) and sexual symptoms such as vaginal dryness (Stead, Fallowfield, Brown, & Selby, 2001; Wenzel et al., 2002), dyspareunia or pain during sexual intercourse (Stead et al., 2001), and decreased libido or sex drive (Ferrell, Smith, Cullinane et al., 2003; Ferrell, Smith, Ervin, Itano, & Melancon, 2003). A longitudinal study by Andersen, Anderson, and DeProse (1989) assessed sexual difficulties in women over time to matched comparison groups: (1) women diagnosed with benign gynecologic disease and (2) healthy women. Results showed decreased frequency of intercourse and sexual excitement for women in both disease groups, although decreased sexual excitement was particularly noticeable in women with cancer (Andersen et al.).

In addition to physical factors, psychological variables such as fear about engaging in sexual activity with a spouse have shown to affect a woman's sense of sexuality and desirability (Stead et al., 2001). For women with ovarian cancer, continuation of sex with their spouses after diagnosis was predicted by the ability to talk about sex with their spouses, the perception that sex could regain normalcy, and the absence of sexual symptoms (Stead et al.). Psychological distress was the key predictor in determining whether sex continued after diagnosis and treatment in that even after the physical symptoms had subsided, the residual effects of decreased self-esteem affected the couples' sex life (Stead et al.). Despite surgical procedures that are less physically evident than, for example, a mastectomy, women with ovarian cancer reported a damaged sense of attractiveness (Ersek, Ferrell, Dow, & Melancon, 1997).

Stead et al. (2001) conducted a qualitative study to understand the effects of an ovarian cancer diagnosis on sexuality and the quality of communication between ovarian patients and their health care providers on issues of sexuality. Interview questions revolved around ovarian cancer patients' current sexual behaviors, response to sex, sex life satisfaction, and the importance of sex. Fifteen women with ovarian cancer, aged 42 to 71, were identified as a sexually active or inactive through a sampling survey. Sexual inactivity was related to the ovarian cancer diagnosis. Participants were 8 to 120 months post diagnosis with median time since diagnosis of 18 months. Additional interviews were conducted with 43 clinicians and nurses to investigate their attitudes and experiences on giving their patients information about sex.

Each semi-structured interview conducted with a participant was audiotaped, transcribed, and analyzed using grounded theory techniques (Stead et al., 2001). Through interviewing, the authors uncovered core sexuality issues women were facing as a result of an ovarian cancer diagnosis. Women described having fears about engaging in sex or being rejected by their partners. Psychological factors played a greater role than physical factors in whether sexual activity continued between a woman and her partner subsequent to cancer. Stead et al. noted that many times the physical symptoms (e.g., vaginal dryness) decreased over time; however, the lingering psychological distress (e.g., lowered self-esteem) permanently affected some women and their romantic relationships. The authors also uncovered women's perceptions about discussing sexual issues with their health care providers. Women believed that their providers should have verbally discussed or given them written information about sexual issues to help normalize the sexual problems they were experiencing. One woman remarked, "I could have understood why I was having sexual problems if they'd have said, 'You might have problems sexually because we've removed this or that.'"

Interviews with the health care professionals showed that 43 out of 44 believed that sexual problems and issues should be communicated with patients (Stead et al., 2001). In reality, only nine physicians and nurses actually discussed sexual issues with their patients. Lack of communication with patients about these issues appeared to be related to lack of knowledge of the sexual problems that can occur after an ovarian cancer diagnosis: "I'm not sure what types of sexual problems patients experience." Other themes included health care providers' embarrassment and lack of confidence in talking

about sexual issues with patients, lack of privacy in the clinic to talk about such problems, and not believing that this topic was part of their responsibility. Stead et al. suggested that health care providers might benefit from educational support to facilitate better communication between them and their patients about sexual issues. A recent pilot study showed that early stage gynecologic cancer patients with sexual dysfunction benefited from a brief, 3-session psychoeducational intervention (Brotto et al., 2008). The participants, who completed pre- and posttest questionnaires and physiologic measures of sexual arousal, reported improvement in sexual response as well as overall quality of life. These results show promise for a brief intervention aimed at helping women with gynecologic cancer develop psychoeducational tools to help manage important issues related to sexuality.

Employment. The need to return to employment has been seen as an indicator of conquering a cancer diagnosis and gaining control (Ferrell, Smith, Ervin et al., 2003). Women with ovarian cancer reported difficulty stopping work in order to receive cancer treatment; most felt relieved when they were able to return to work after regaining their health (Ferrell, Smith, Ervin et al.). Quality of life and mental health of endometrial and cervical cancer survivors have also been shown to be associated with employment status (Bradley, Rose, Lutgendorf, Costanzo, & Anderson, 2006). Compared to survivors who were disabled or homemakers or retired, survivors who worked full-time reported fewer depressive symptoms. Even survivors who worked part-time reported fewer depressive symptoms than cancer survivors who identified themselves as disabled. In general, part-time and full-time working survivors reported fewer depressive symptoms than survivors

who were homemakers, disabled, or retired did (Bradley et al.). These findings were similar to the results of a qualitative study of cancer survivors in Denmark, demonstrating the importance of employment to overall well being across cultures and cancer populations (Rasmussen & Elverdam, 2008). For these 23 cancer survivors, being able to return to work after cancer treatment helped to establish goals and structure and provided a “normal existence.” On a more existential level, work imbued life with meaning and gave participants a sense of social identity. For those who were unable to return to work, the goal was to find new activities that provided challenge, meaning, and structure (Rasmussen & Elverdam).

Quality of life. A mixed model study by Ersek et al. (1997) used qualitative and quantitative approaches to investigate quality of life (the subjective evaluation of the positive or negative of attributes that characterize one’s life) in women diagnosed with all stages of ovarian cancer ($N = 152$). Quality of life was assessed by the Demographic Tool-Cancer Survivors and Quality of Life Scale-Cancer Survivors (QOL-CS), a 41-item instrument developed by Ferrell, Dow, and Grant (1995). For each item, response choices range from 0 (*worst outcome*) to 10 (*best outcome*). The following results were found for the four domains of well being as measured by the QOL-CS: physical ($M = 7.19$, $SD = 1.86$), psychological ($M = 5.48$, $SD = 1.68$), social ($M = 5.93$, $SD = 2.04$), and spiritual ($M = 6.77$, $SD = 1.67$). The mean overall quality of life score was 6.13 ($SD = 1.42$). Participants in an active disease state had significantly lower physical, ($p = .001$), psychological ($p = .05$), and social ($p = .02$) well-being as well as lower overall quality of life ($p = .001$) than those who reported being in an inactive disease state.

Participants were also asked to answer open-ended questions: (1) “What does quality of life mean to you?” and (2) “How has the experience of cancer impacted your quality of life? How has your quality of life changed?” The third question asked participants to write down a personal experience related to their cancer diagnosis and subsequent quality of life. Participants frequently reported happiness and enjoyment, living life to fullest, and learning how to appreciate the small things. In addition, participants cited changing attitudes, living for the present moment, appreciating life, and not taking things for granted as important components of quality of life.

In another qualitative study, Ashing-Giwa et al. (2004) interviewed key-informants ($N = 23$), such as physicians, nurses, and health administrators to understand the various psychosocial factors related to quality of life in women with cervical cancer. Results from the key-informant interviews demonstrated the complexity and multi-faceted nature of a cervical cancer diagnosis and how certain factors play major roles in determining health-related quality of life in patients. The key-informants cited cultural and socio-ecological factors as well as how women with cervical cancer define and deal with their diagnosis as powerful influences on health-related quality of life. The complexity and difficulty in navigating through the U.S. health care system was cited as a major barrier in seeking and receiving adequate health care for minority women. Informants believed that the ways to mitigate stress and increase quality of life for patients were to boost the number of support systems in health care settings and to increase cultural sensitivity among medical staff. Last, key-informants discussed the importance of religion and spirituality among minority women with cervical cancer and

the benefits (e.g., coping resource) and consequences (e.g., divine punishment) of such practices.

In addition to the key-informants interviews, Ashing-Giwa et al. (2004) conducted focus groups with 51 ethnically diverse women with cervical cancer. The groups were designed to assess factors important to health-related quality of life. Participants were divided into four focus groups based on ethnicity (i.e., African Americans, Asian Americans, Caucasians, and Latinas) and spoken language (i.e., English, Spanish, and Chinese). Focus group questions revolved around pre-determined domains: health beliefs, health socialization, relationships, quality of care, socioeconomic status, and socio-ecological factors. Examples of questions asked were “What are things that have helped your recovery the most?” and “Thinking back to childhood, what were some of the things you learnt about health?”

Among the four groups, women reported family support, spirituality, and quality of medical care as important variables for the road to recovery. Across all groups was the consensus that social support was not only important to emotional quality of life but also to treatment adherence. Women cited a need for greater available resources in health care settings such as affordable follow-up care and support groups. Concerns included side effects related to treatment, language barriers with health care providers, lack of control over treatments, employment issues, and sexuality. Ethnic differences were also noted. Cultural and family factors generally contributed to overall well-being; however, cultural conflicts with the health care system sometimes impeded women in seeking health care, specifically for Latinas and Asian Americans. Strong religious views, such

as faith in God, were frequently cited for support and strength among most of the women, particularly in the African American and Latina participants. In general, socioeconomic status, ethnicity, cultural beliefs, age, and family support dictated the level of cancer-related burden (Ashing-Giwa et al, 2004).

The study demonstrated the importance of understanding the effects of key psychosocial and ecological factors on overall quality of life (Ashing-Giwa et al., 2004). Findings illuminate the physical, psychological, and systemic issues that plague many women with cervical cancer. However, as with many other diseases, minority women are disproportionately affected by cervical cancer due to lack of health care knowledge and access. Ashing-Giwa et al. suggested that further research is needed in order to better understand key cultural, social, and ecological variables that might play mediating roles in health-related quality of life in women with cervical cancer.

Bradley et al. (2006) examined quality of life and mood in 152 long-term survivors of cervical and endometrial cancer. Eligible survivors were women who had been diagnosed with cervical or endometrial cancer within the past 5 to 20 years with no secondary cancer diagnoses. Eighty-nine healthy controls, women receiving a gynecologic exam at a clinic, were identified and recruited. The majority of participants, in all groups, identified as Caucasian/White (95.9%), were married or living with a partner (59%), had at least a high school diploma (33%), had an income of greater than \$50,000 (22.3%), and worked full-time (38%). Results showed that there were no significant differences in quality of life or depressive symptoms among the three groups. However, cervical cancer survivors reported more anxiety than endometrial survivors did,

and more dysphoria, anger, and confusion than the other two groups. Overall, greater depression and mood disturbance were reported by women who were unemployed and unmarried. Treatment modality, stage of disease, and length of time since diagnosis were unrelated to quality of life or mood.

Costanzo, Lutgendorf, Rothrock, and Anderson (2006) examined the use of engagement and avoidant coping strategies among advanced stage gynecologic cancer patients who were facing long-term stressors of chemotherapy and advanced disease. Women were more likely to utilize strategies such as active coping, seeking social support, and mental disengagement. Engagement coping (active coping and seeking social support) was unrelated to quality of life or mood. Avoidant coping (disengagement and cognitive avoidance) was associated with lower quality of life and greater distressed mood. In sum, coping patterns and outcomes may be more pronounced among cancer patients dealing with severe disease and extensive treatment. Further, avoidant coping may be detrimental with respect to mood and quality of life (Costanzo et al.).

In women with ovarian cancer, the role of religion and spirituality, coping, and quality of life were examined (Canada et al., 2006). Majority of the women ($N = 129$) were Caucasian, married, and had some college education. Eighty-five percent of participants had Stage III or IV cancer at study entry. Pearson correlations revealed that religion and spirituality was related to active coping, overall quality of life, emotional and functional well-being, and fewer ovarian-cancer specific concerns. Active coping was related to overall quality of life and social and functional well-being. Religion and

spirituality and overall quality of life were mediated through the use of active coping (Canada et al.). Further, a study examining posttraumatic growth, which includes positive changes as a result of coping with a stressful or traumatic event, in a sample 183 Hispanic and Non-Hispanic White cervical cancer patients, found that participants with greater spirituality reported greater posttraumatic growth (Smith, Dalen, Bernard, & Baumgartner, 2008).

Despite higher levels of psychological distress and lower quality of life among women with gynecologic malignancies in comparison to healthy controls, studies have shown that quality of life generally tends to improve over time for survivors (Anderson & Lutgendorf, 2000; Bradley et al., 2006).

Interpersonal relationships. Women with ovarian cancer described a keen sense of loneliness that made them feel as if they were alone in fighting the ovarian cancer battle (Ferrell, Smith, Ervin et al., 2003). Support from other women with the same diagnosis would provide a “safe haven” and help create bonds with fellow patients to build confidence, comfort, and hope for survival. Many reported positive changes in their romantic relationships such as feeling emotionally closer to their spouse. Husbands of wives with ovarian cancer also reported similar shifts in the spousal relationship, citing strengthening of partnership and willingness to share the burden of cancer as major changes to the marital unit (Ponto & Barton, 2008). Women were also concerned about the added responsibilities to their family and the burden of their diagnosis (Ferrell, Smith, Ervin et al.).

A cross-sectional study investigated the mediational roles of perceived control and self-esteem between illness-related stress (physical impairment), interpersonal stress (family and friend unsupportive interactions), and psychological distress in 143 ovarian cancer patients (Norton et al., 2005). Results suggest that perceived control and self-esteem are the mechanisms (i.e., mediators) by which illness-related and interpersonal stress are related to psychological distress. Specifically, higher levels of physical impairment were related to lower perceived control and, in turn, with greater psychological distress. In addition, higher levels of unsupportive behaviors from family and friends were related to lower self-esteem and, in turn, with greater psychological distress (Norton et al.). Conversely, other studies have not found unsupportive family behaviors as closely related to gynecologic cancer patient distress as alternative factors. A systematic review of ovarian cancer studies identified the following factors as playing important roles in the manifestation of depression and/or anxiety symptoms: younger age, advanced disease, greater frequency of physical symptoms, and recent diagnosis (Arden-Close, Gidron, & Moss-Morris, 2008). Although methodological differences may account for the discrepancies in findings about the role of interpersonal relationships in patient psychological health, most individuals with cancer do not endure the cancer experience alone and for some, their ties to their families are inextricable (see Koldjeski, Kirkpatrick, Everett, Brown, & Swanson, 2007).

Symptom management. The various physical symptoms patients must endure during the course of rigorous and lengthy cancer treatment are well documented (e.g., Doyle, Crump, Pintilie, & Oza, 2001; Fitch, Gray, & Franssen, 2000). Chemotherapy

alone produces side effects such as nausea, diarrhea, appetite loss, and fatigue that can severely disrupt quality of life and daily functioning of an individual with cancer (Ferrell, Smith, Cullinane et al., 2003; Lakusta et al., 2001).

Ferrell, Smith, Cullinane et al. (2003) gathered data from a newsletter, created in response to the lack of support for women with ovarian cancer, to document symptom concerns of ovarian cancer patients. A total of 21,806 letters, cards, and e-mails had been amassed at the time of data analysis.

Symptom concerns were identified and divided into pre- and post-diagnostic concerns. Of the comments related to pre-diagnostic symptoms, the most frequently reported were related to bloating and abdominal swelling, fatigue (“Every time I climb a flight of stairs, it feels like Mt. Everest”), abdominal or pelvic pain (“I had severe pain in abdomen, legs, and feet....I went up to my room with a towel and cried with my pain”) and urinary frequency. Of the comments on post-diagnosis concerns, the most frequent were about pain, including aches and neuropathy (“It felt as if my feet were in too-tight ski boots that I could not remove”). Findings illustrate the numerous symptoms women with ovarian cancer must manage on a daily basis (Ferrell, Smith, Cullinane et al., 2003).

Review of the gynecologic cancer literature highlights the variety of physical, psychological, and social challenges faced by women with ovarian, endometrial, and cervical cancer, the most common types of gynecologic cancers. In addition to distress and depression, these women often experience physical and sexual symptoms that leave them feeling fatigued, depleted, and alienated from themselves and others.

Because gynecologic cancer is, by definition gender-specific, unique issues arise in response to the disease. As previously mentioned, the majority of cancer studies investigate psychological and psychosocial factors that are easily accessed via self-report questionnaires (Cella & Tross, 1987). As a result, the findings from these studies measure only limited aspects of the cancer experience. To further limit their usefulness, the findings are disjointed, offering no integrated description of the cancer experience. What is missing is an approach to gynecologic cancer that ties these findings together conceptually and that offers the beginning of an explanation of why gynecologic cancer affects its victims in the ways that it does.

Kübler-Ross (1969) and other, more existential writers might argue that the universal fear of death is the missing piece of the puzzle. A relatively new area within existential psychology, Terror Management Theory (TMT; Koole et al., 2006; Pyszczynski et al., 2003), offers a perspective from which the seemingly disparate findings of the extant literature might be integrated. Terror, as defined by TMT researchers, refers to “a uniquely human response to the threat of annihilation” (Pyszczynski et al., 2003, p. 8). TMT posits death anxiety as the principal force behind a wide range of human social behaviors.

At first glance, constructs such as social support appear to be distinct from death anxiety. However, TMT studies have repeatedly found empirical support for the use of psychological and social structures (such as social support), in helping individuals restore psychological equanimity when faced with the threat of death (e.g., Arndt et al., 2002). Although other social psychology theories such intergroup behavior (see Tajfel, 1982)

may also help to explain much of how and why we behave, TMT provides a particularly useful way of understanding the gynecologic cancer experience because of its emphasis on death anxiety as the primary underlying motivation for human behavior. Given the inherent link between a cancer diagnosis and a resulting increase in death anxiety, examining this facet of the cancer experience might offer new insights into one of the important underlying causes of other, more visible symptoms. Further, this approach allows the gynecologic cancer experience to be situated within the context of a broader understanding of how humans react to life threatening events.

The next sections will provide an overview of TMT, the intersection between findings from the gynecologic cancer literature and TMT, and a review of TMT studies on cancer and illness to provide an integrated understanding of the cancer experience.

The Problem of Death

Cultural anthropologist Ernest Becker (1973), author of the Pulitzer Prize winning book *The Denial of Death*, synthesized the ideas of Rank, Kierkegaard, and Freud with his own to understand the central role of the “terror of death” in human motivation. This fear, he posits, is the basic unconscious and underlying motivation for all human behavior. Becker maintains that human beings face a frightening paradox unique to our species: an intense, innate desire for continued existence, coupled with the capacity to recognize the futility of that aim. He writes,

...the essence of man is really his paradoxical nature, the fact that he is half animal and half symbolic.... He has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order blindly and dumbly to rot and disappear forever (Becker, 1973, p. 26).

Millions of years of evolution have granted humans cognitive abilities unknown in other animals: the ability to remember past events and anticipate future ones and to reflect rather than simply react (Becker, 1973). In other words, we are “aware of [our own] awareness” (Pyszczynski et al., 2003, p. 15) and the world around us. Yet, having this ability comes with a price: the capacity to feel “fear, trepidation, anxiety, alarm, fright, horror, and in due course, unmitigated terror” (Pyszczynski et al., p. 15). This unmitigated terror comes from the awareness that death is inevitable. To put it bluntly, at the most basic level we are little more than “sentient pieces of breathing, defecating, menstruating, fornicating, expectorating, ejaculating meat—no more fundamentally significant or enduring than a fly hovering over a fresh pile of poodle feces, or the poodle that produced it” (Solomon, Greenberg, and Pyszczynski, 2003, p. 459).

In an “animal instinctively programmed for self-preservation and existence” (Dechesne et al., 2003, p. 723) with the cognitive capacity to recognize the inevitability of death, the development of death anxiety is the natural result. The natural response to this anxiety is the creation of a “vital lie,” wherein we deny our mortality by tying our very sense of personal meaning to shared cultural beliefs that continue to function even after we die (Becker, 1973). The result of this is that we work to create a culture designed primarily to function as an elaborate death-denying system. According to Becker, the creation of culture as a death-denying system is a largely out of awareness for most of us. In his seminal end-of-life book *The Way We Are*, Allen Wheelis (2006) describes this underlying process keenly:

I am obsessed with death; and this obsession, I am convinced, is not a private terror but the unchanging backdrop to the stage of our existence.

We block it from view with contrived sets that we call reality, and though we know those sets to be fake we labor endlessly to make them look real. And as we go about those actions on that stage which accord with those steps, we come finally to believe they *are* real. The backdrop behind them is forgotten (p. 18).

This backdrop consists of the intricate social patterns of relating and behaving that define culture. Within them, our behavior is constrained by certain rules, but from them we derive a sense of ourselves as part of something larger—something that is bigger than us and, as a result, capable of enduring even when we do not. We seek to gain approval from our social group and an accompanying sense of belonging by not only following, but actually embodying these shared values.

The crux of Becker's idea is that humans attempt to transcend the fear of death by attaining symbolic immortality. The specific nature of this immortality is defined by the specific symbols inherent in the culture. So, for example, in one culture symbolic immortality is attained by fighting against a shared enemy, in another by writing an important piece of music, in yet another by designing a monument that endures through the ages. These culturally prescribed acts of heroism (or *causa sui*) create lasting meaning.

By participating in heroic acts, we invest in our culture and thus, become part of something larger than our self, something that will last beyond our physical body. In practice, this takes many forms. In American society, individuals who acquire vast amounts of wealth and power, write a compelling piece of literature, or earn a star on the Hollywood Walk of Fame tend to be seen as modern day heroes. Their existence has been immortalized through namesake foundations, top selling books, or a personalized

star imbedded in a concrete sidewalk. In the academic community, faculty gain a similar feeling by publishing important research findings and passing on knowledge to students.

Becker's point is that overcoming death via symbolic immortality is the fundamental goal of all humans. It is not rare or unusual, but instead an inherent part of being human. We *all* strive to achieve immortality—no exceptions. And, we do so in a variety of ways, sometimes consciously, as when we adhere to specific religious tenets in an attempt to achieve literal immortality in the form of an afterlife. But, most of the time, unconsciously through things like bearing children in the hope that one day they will “follow in our footsteps,” or donating a hospital wing in the family's name, or serving as a soldier for our country. The list could go on and on. By successfully immersing ourselves in a larger cultural system, we are reassured by the belief that we have created a purposeful life and lasting significance in a seemingly infinite universe (Becker, 1973; Brown, 1959).

Drawn to and intrigued by Becker's work, social scientists began to empirically test how people managed this existential paradox. Terror Management Theory (TMT; Koole et al., 2006; Pyszczynski et al., 2003), a modern offshoot of Becker's ideas, explores the kinds of behaviors we engage in to transcend the problem of death. In other words, how do we respond to or react in situations that remind us of our own mortality? TMT provides an empirically based framework in which to understand a wide range of human behaviors in response to threats of literal and symbolic death, including tragic historical events such as September 11th.

Terror Management Theory

Terror Management Theory (Koole et al., 2006; Pyszczynski et al., 2003) was created from repeated findings that, in the wake of events that reminds individuals of their own death, faith in shared worldviews intensifies and efforts to enhance self-esteem increase. Research based on this theory now encompasses more than 200 published studies (Koole et al., 2006) in 30 different countries. TMT posits that culture (or shared beliefs about the nature of reality) reduces anxiety about death by providing us with a cultural worldview—prescriptions on how to make sense of the universe and behave in certain ways to achieve success in the world. Simply put, culture gives us a sense of meaning and purpose in life. In turn, this allows us to perceive ourselves as persons of worth (or as heroes according to Becker) within our culture while concurrently enhancing our self-esteem.

The key psychological role of self-esteem, therefore, is to buffer or reduce existential anxiety by giving us a sense that we are of value in the universe, making self-esteem a universally necessary psychological function in all individuals (Pyszczynski, Greenberg, Solomon, Arndt, & Schimel, 2004). The ways in which individuals acquire self-esteem differ and depend largely on the cultural context. For some individuals, behaving in ritualistic and prescribed ways in the world grants the ultimate prize—literal immortality in the form of an afterlife. Conversely, what happens when the death-denying function of culture fails us because of an event that forces us to consciously think about our own deaths? TMT studies have consistently demonstrated that reminders of our own mortality (or *mortality salience*; Solomon et al., 2003) motivate individuals to

respond to this threat of death by strengthening their cultural worldviews through a myriad of social behaviors. TMT holds several assumptions about the nature of people:

1. We have an innate instinct to live.
2. We rely on culture, or humanly constructed shared beliefs about the nature of reality, to gain a sense of approval and purpose in life.
3. Cultural approval gives us a sense of individual self-esteem that buffers death-related anxiety so that we can function in the world.
4. In the event we are forced to face our mortality, our cultural beliefs deepen and we engage in behaviors to reinforce those beliefs.

A recent example is the September 11th attacks in 2001. In *In the Wake of 9/11*, Pyszczynski et al. (2003) uses this historical event as an example to explain the psychological ways in which the American people managed the fear of dying engendered by the terrorist attacks. As the celebration of American culture intensified in the aftermath of the attacks, American flags began flying off retail shelves. Songs about the glory of America were played repeatedly on the radio. Church attendance surged. And, President George W. Bush was re-elected for a second term after declaring war on the “Axis of Evil.” At the same time, individuals deemed “non-American” became targets of violent and xenophobic retaliation (Pyszczynski et al.). These types of reactions and behaviors subsequent to 9/11 can be explained by a number of social psychology theories. For example, the events following the terrorist attacks could be explained in terms of group biases whereby Americans attempted to band together (ingroup) to strengthen a sense of belongingness and deride those deemed “foreign” (outgroup) as a

way to restore self-esteem in a time of uncertainty (see Tajfel, 1982). From a more existential viewpoint such as TMT, these behaviors confirmed what studies have demonstrated for 20 years, namely that “psychological forces... promote... fierce allegiance to these systems of meaning and the readiness to annihilate those with different perspectives” (Koole et al., 2006).

The mortality salience and self-esteem as an anxiety buffer hypotheses. Two main premises of TMT are that (1) self-esteem serves as a buffer against anxiety and (2) reminders of death (or mortality salience) lead individuals to strengthen their cultural worldviews. From the TMT perspective, self-esteem, derived from culture, is the psychological mechanism by which death anxiety is managed. Therefore, mortality salient conditions (or reminders of one’s own mortality) should enhance the individual’s need to attain a greater sense of self-esteem by positively reacting to those who endorse a similar cultural worldview and negatively reacting to those who undermine it (Koole et al., 2006). Experimental manipulations in laboratories provide the setting for which these hypotheses have been tested.

Self-esteem is one of the most widely studied constructs in social science research (Carvajal, Evans, Nash, & Getz, 2002). Studies on the relation between self-esteem and anxiety have consistently produced a negative correlation: higher levels of self-esteem are associated with lower levels of anxiety (for a review see Pyszczynski et al., 2004). The first TMT study to examine the role of self-esteem as an anxiety buffer involved recruiting college students to participate in a supposed “personality” study. To temporarily elevate or lower levels of self-esteem, participants were given mock

personality feedback (neutral or positive) after completing a set of standard personality measures (Greenberg et al., 1992). The neutral feedback statement contained two sentences: “*Although you have some personality weaknesses, you are generally able to compensate for them*” and “*Some of your aspirations may be a bit unrealistic.*” In the positive feedback condition, the feedback stated, “*Although you may feel that you have some personality weaknesses, your personality is fundamentally strong*” and “*Most of your aspirations tend to be pretty realistic.*”

Subsequent to the feedback, participants in the mortality salient condition were exposed to electrocution and autopsy video footages whereas those in the control condition were shown neutral footage of the same duration. The dependent variable, level of anxiety, was assessed by the State Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1970) at the end of the study. Participants who received neutral personality feedback reported higher levels of anxiety after watching the death-related footage versus participants in the same condition who received positive personality feedback. Results demonstrated support that higher self-esteem is negatively correlated with anxiety (Greenberg et al., 1992; Study 1). A subsequent study showed corroborating evidence for self-esteem as an anxiety buffer through the use of more objective dependent measures (Greenberg et al.; Study 2). In this experiment, self-esteem was manipulated by receiving mock feedback from an intelligence test. Participants in the experimental group, who were anticipating electrical shocks, had greater arousal levels (measured by skin conductance) than those who were expecting to

examine colored lights. When self-esteem levels were elevated through positive mock feedback, increased levels of arousal in the electrical shock condition disappeared.

Over 100 studies have been conducted to investigate the effects of mortality salience, the second hypothesis, on human behaviors such as aggression, risk taking, creativity, stereotyping, and perceptions about dissimilar or similar others (Koole et al., 2006; Solomon et al., 2003). Because of the large number of studies that have tested this hypothesis, the general procedures for how these studies are conducted and highlights of selected “classic” experiments will be given.

Participants, generally undergraduate students in an introduction to psychology course, are told that they are participating in a personality study. After being randomly assigned to one of two groups, they are then given standard personality measures to complete (Pyszczynski et al, 2003). One condition is the mortality salient group in which participants are exposed to stimuli designed to prime individuals to temporarily think about their own mortality. This is achieved through several methods, the most common method by inserting open-ended items between the personality measures. The items are typically written as: “*Please briefly describe the emotions that the thought of your own death arouse in you,*” and “*Not down, as specifically as you can, what you think will happen to you as you physically die.*” Those in the control group also answer open-ended items; however, those items revolve more innocuous topics than death such as experiences of social rejection, dental pain, or failing a test.

After completing the questionnaires, participants are then given the chance (designed to appear as a separate study) to assess individuals who share or differ from

their cultural worldviews, the outcome variable. A study by Greenberg et al. (1990) examined the effects of mortality salience on attitudes toward individuals of different religious beliefs. Self-described Christian participants were asked to evaluate Christian and Jewish individuals who were depicted as similar to one another with the exception of religious backgrounds. Participants assigned to the mortality salient condition reported more favorable attitudes towards the Christian individuals and more negative attitudes towards the Jewish individual. There were no statistically significant differences in attitudes towards the Christian and Jewish targets of the participants in the control condition.

Other studies demonstrate the effects of mortality salience on actual human behavior. McGregor et al. (1998) investigated the effects of mortality salience on aggressive behaviors in self-reported liberal and conservative college students. Participants were asked read an essay supposedly written by another student in the study that criticized either liberals or conservatives. After being exposed to a mortality salient or control condition, participants were asked as part of a “second” study to dispense hot sauce in the amount of their choosing for the student who wrote the essay. The student, as told to the participants, did not like foods that were spicy. In the control group, participants administered similar amounts of hot sauce regardless of whether the student was of a different political belief system. Those in the mortality salient condition dispensed double the amount of hot sauce to the student of a differing political background than to the student of a similar background. Studies conducted in Germany, Canada, Israel, Italy, the Netherlands, and Australia found similar findings in that

mortality salience engenders the need for worldview defense against those who threaten it (Solomon et al., 2003).

The TMT studies illustrated above demonstrate empirical support for the wide variety of social behaviors individuals use to help restore psychological equanimity when faced with the threat of death. The following section is a synthesis of the findings from the gynecologic cancer literature within a framework of terror management to paint a more cohesive picture of the gynecologic cancer experience.

Social support was identified as a crucial component to quality of life in women with gynecologic cancer (e.g., Ashing-Giwa et al., 2004). Based on the McGregor et al. (1998) and Greenberg et al. (1990) studies, mortality salient conditions produce more favorable attitudes and behaviors towards similar than dissimilar individuals. Consistent with TMT findings, women with gynecologic cancer naturally gravitate towards individuals who share their values and worldviews. This social bonding offers the mechanism by which the woman restores self-esteem through identification with similar others. In the Greenberg et al. (1990) study, participants were more inclined to intensify their religious beliefs after being reminded of their mortality. Within the context of TMT, the need for religious and spiritual beliefs in women with gynecologic cancer can be seen as a way to regain self-esteem (via a sense of purpose and belonging) to buffer death anxiety.

Another key finding among women with gynecologic cancer is the difficulty in resuming sexual activities with their spouse as a result of psychological distress (e.g., Ersek et al., 1997; Ferrell, Smith, Cullinane et al., 2003). From a terror management

perspective, sexual attitudes and behaviors are related to death anxiety because sex reminds us of our primitive “creatureliness” or animal nature. Becker (1973) wrote, “sex and death are twins....Animals who procreate, die. Their relatively short life span is somehow connected with their procreation” (p. 163). A series of three TMT-based studies showed the effects of mortality salience on attitudes toward sex in individuals with high or low neuroticism (Goldenberg, Pyszczynski, McCoy, Greenberg, and Solomon, 1999). Neuroticism was examined because of repeated findings that this personality trait was positively correlated to disgust, including repulsion of sexual acts. After being reminded of their mortality, high neuroticism participants reported less interest in the physical aspects of sex, which in turn, increased death thought accessibility. However, after participants were primed to think about love, there was decreased accessibility of death-related thoughts in reaction to the physical aspects of sex. In other words, priming high neuroticism participants to think about sex as a meaningful, non-animal experience buffered death-related thoughts. Though these studies were conducted in healthy samples, findings offer a glimpse into the unconscious processes that may play a role in the cancer patient’s perceptions of sex.

Intersection of Terror Management Theory and Cancer

Although recent studies on TMT have expanded to investigate health-related attitudes and behaviors as way to assuage perceived vulnerability to a health threat (Arndt, Routledge, & Goldenberg, 2006), few have examined the effects of having cancer on attitudes and behaviors. A quick literature search in prominent academic databases (i.e., PubMed and PsycInfo), using key search terms of “terror management theory” and

“cancer,” yielded a total of five studies. Two of the five studies will be reviewed. The first study is directly relevant to the present study because of its investigation of mortality salience in a cancer sample. The second study, a series of five smaller studies, will be reviewed in order to highlight the powerful psychological defenses employed by individuals to manage the fear of cancer and death. In addition, the methodology and limitations of each study will be discussed as well as the unique contribution of the present study.

Little and Sayers (2004) conducted a study utilizing TMT as a framework to examine social bond strengthening between cancer survivors and their family and friends. According to TMT, individuals diagnosed with cancer (primed by their diagnosis) would reach out to their primary social group for reassurance and self-esteem to buffer feelings of death anxiety. The study was conducted in response to empirical evidence that suggests individuals do not always turn to social groups after being reminded of their mortality. Based prior research, the authors offer a continuum of death awareness categorized by time and a state of being: (1) mortality salience, which occurs during and immediately post diagnosis and treatment, (2) death salience, during remission where the survivor is hit with the reality that they could have just as easily died than survived, and (3) dying salience, during which the person is terminally ill and aware of the “imminence of personal death, and of the move away from the immediacy and experience of living the world” (Little & Sayers, p. 19). Fifteen cancer patients were interviewed.

The authors found that mortality salient conditions, as predicted by TMT, foster outreach toward social groups for reassurance soon after the cancer diagnosis has been

made (Little & Sayers, 2004). Survivors reported feeling a will to live and camaraderie among family members and friends to fight and win the cancer battle: “When you were sick, there was a purpose to life. To get better. Everyone agreed that was the most important thing” (p. 192). Although some participants entertained the possibility of dying from cancer, most reported believing that their treatment would work and that they would ultimately “beat” cancer (Little & Sayers). The authors found that it was during the mortality salient conditions where the largest number of participants joined cancer support groups and offered to help counsel other cancer patients.

According to Little and Sayers (2004), after the 2-year post diagnosis “honeymoon phase” has worn off, survivors tend to enter death salience. Survivors in this phase generally reported a decline in wanting to talk about their cancer experience and retreated from any public displays (e.g., support groups) to discuss their cancer diagnosis. The authors posit that these behaviors may be explained by the sudden explicit awareness that death could have occurred just as easily as surviving. Survivors begin to turn toward themselves to question the meaning of their lives. One participant reported suddenly having a “glimpse of death....and investigating death in that sort of artistic way, but also emotional way and what it means and stuff” (p. 194). Survivors in this state of being struggle to regain psychological equanimity after the battle for survival has subsided in intensity.

The last phase, dying salience, elicits behaviors among cancer survivors contrary to those found during the mortality salience phase. Participants reported that communication with their family dissolved during this phase because of the inability to

describe to the family their feelings and thoughts as a person dying: "...I don't know what I can say. I want to do it because they want it, but I can't put it down. I can't bring it out of my mouth what I want to say....What are you supposed to talk about?" (p. 195). Little and Sayers (2004) suggested that communication breakdown, starting to become evident in the death salience phase, may be a result of cancer patients and their families being in different death awareness phases. For example, patients in the post-treatment process of their cancer experience may begin to reflect on the meaning of their lives, whereas family members may still be in the mortality salient phase of encouraging them to reach out to the family.

As predicted by TMT, patients in the mortality salience phase, prompted by a diagnosis of cancer, showed greater outreach for members of their social group (Little & Sayers, 2004). Conversely, survivors in the death and dying phases showed that the bonds with their social group did not continually strengthen as survivors moved further away from time since initial diagnosis. This finding does not diminish the theoretical power of TMT, but rather demonstrates the complexity of death anxiety and the fundamental internal changes patients may undergo during their cancer experience. Kübler-Ross (1969) illustrated the fluidity of this gradual awareness toward death in her stages of grief.

A limitation of the Little and Sayers (2004) study is that data were categorized based on predetermined categories of death awareness phases rather than allowing categories to naturally emerge from participant language. The study illustrates the potential importance of having survivors speak with other patients in a similar rather than

dissimilar death awareness phase. Findings also provide insight into factors that would help patients in death or dying salient phases increase family bonds and strengthen interpersonal relationships.

A series of five studies by Arndt, Cook, Goldenberg, and Cox (2007) were conducted to understand the cognitive processes of mental suppression and activation in relation to thinking about cancer. Based on prior research, the authors hypothesized that priming individuals to think about having cancer would increase accessibility to thoughts related to death (normally suppressed under non-threatening conditions) only after a slight delay or high cognitive load (Arndt et al.). A delay or distraction would be necessary to “relax” the first line of defense in the event of mortality salience: thought suppression. Studies suggest that accessibility to death-related thoughts increases when these thoughts are on the periphery rather than the focal point of attention (e.g., Greenberg, Pyszczynski, Solomon, Simon, & Breus, 1994). Cancer as the mortality salient condition was chosen because of its tangible nature in relation to the more abstract concept of death and dying. These studies were designed to address the association of disease and death-related thought, relatively understudied within the area of TMT. Samples for all five studies were college undergraduates (largely Caucasian) recruited from introductory to psychology courses, one of the limitations of TMT research.

The first study explored the basic question of whether priming participants to think about having cancer would increase the accessibility to death-related thoughts as would priming individuals to think about their own mortality (Arndt et al., 2007). The sample consisted of 50 female students, randomly assigned to one of three groups: (1)

mortality salient, (2) cancer salient, and (3) dental salient. Similar to previous studies on mortality salience, participants were given two open-ended items that asked them to write about their emotions when they thought about the salient condition presented to them (i.e., death, cancer, or dental pain) and what they believed would physically happen to them as a result of the condition. Dental pain was chosen because it is an aversive but qualitatively different situation than cancer. To foster delay after the experimental manipulations, participants were given a word search puzzle containing words related to television programming (e.g., *soap opera*, *sitcom*, *satellite*). After the delay task, participants were asked to fill out a word completion task, the outcome variable of the study. The task was designed to measure the accessibility of death-related thoughts. Each participant was given 26 word fragments. Of these, eight could be completed using a relatively neutral word or a death-related word. An example of a word fragment was COFF_ _ , which could be completed to spell either “coffee” (neutral) or “coffin” (death-related).

Participants in the mortality salient condition showed increased death-thought accessibility in comparison to those in the control condition (Arndt et al., 2007). Further, mortality salient participants demonstrated greater levels of accessibility to death thoughts than the cancer and dental pain control groups combined. Although the results were consistent with previous findings that mortality salience increases accessibility to death thoughts, the hypothesis that cancer salience would produce the same effects was not supported. The authors suggested that because it is unlikely that a cancer diagnosis

would not elicit death-related thoughts, it might be that the threat of having cancer calls for even stronger cognitive suppression.

Based on results from Study 1, Study 2 was designed to investigate whether a high cognitive load would decrease the effectiveness of thought suppression after thinking about having cancer (Arndt et al., 2007). In other words, individuals under high cognitive load would be cognitively taxed and thus, would be less likely to have the resources to effectively use thought suppression after being primed to think about cancer. Forty-four female participants were divided into two conditions: cancer salient and dental salient. Similar to Study 1, participants were given a packet of questionnaires to complete, including the two-open ended items related to cancer or dental pain. Cognitive load was induced by asking participants to look at a 10-digit sequence for 30 seconds before the numbers were erased. Participants in the low cognitive load were asked to recall and write down the numerical sequence before being given the cancer or dental pain items, whereas those in the high cognitive load were asked to recall the numbers after completing the last measure on death thought accessibility. Death thought accessibility was measured by the same 26 word fragments used in Study 1. Results revealed that the hypothesis was supported: participants in the cancer salient condition demonstrated higher accessibility to death thoughts when under a high cognitive load versus those under a low cognitive load. Further, death thought accessibility was greater in the cancer condition than the dental pain condition. Consistent with Study 1, there were no statistically significant differences found between the cancer and control groups under low cognitive load conditions. Further, there were no statistically significant

differences between the high and low cognitive load participants in the dental pain condition.

Study 3 extended the findings of Study 2 by including a mortality salient condition to compare with a cancer salient condition (Arndt et al., 2007). The researchers hypothesized that because explicit priming about mortality or cancer tended to activate thought suppression, then priming outside of consciousness would negate the need for this defense. To prime participants outside of consciousness, subliminal priming was used by flashing the words *death*, *cancer*, and *fail* across a computer screen. The hypothesis was that subliminally priming participants with either of the first two words would lead them to experience increased accessibility to thoughts about death. Failing a test was used as the control condition instead of dental pain in Study 3 because the threat of failing a task is personally relevant as is a cancer diagnosis.

The sample consisted of 55 undergraduate students, 43 of whom were males (Arndt et al., 2007). Described as a study to understand perceptions of word relationships, participants were asked to sit in front of a computer situated within a cubicle. The first measure was a word relationship task. Two words were presented on the screen, such as *rose* and *flower*. If the words were related, participants were to press the right shift key; however, if the words were unrelated (e.g., *sneaker* and *fajita*), they were to press the left shift key. Between the two mask words were the subliminal prime words, which flashed across the screen for 28 ms. The second computer-based survey, designed as the dependent measure, required participants to determine if the presented string of letters represented an actual word (right shift key) or a nonword (left shift key).

Participants were instructed to respond as quickly and accurately as possible. Each participant completed 60 trials containing four word types: nonwords (e.g., quert), negative words (e.g., torture), neutral words (e.g., doormat), and death words (e.g., dead). Software recorded the reaction times of the participants. After completion of both tasks, participants were assessed to examine whether they recognized the subliminal prime words. None of the participants reported or accurately guessed the prime words.

Results supported the hypotheses (Arndt et al., 2007). Participants in the death and cancer conditions showed faster reaction times to the death words than those in the fail condition; reaction times for the death and cancer conditions did not significantly differ. There were no significant reaction time differences among all three conditions for the negative words. Findings from Study 3 demonstrate that subliminal priming of cancer and death increases accessibility to death thoughts, whereas in Study 1, explicit priming increased death thoughts only in the mortality salient condition.

Study 4 investigated the conditions under which death thought suppression would be more or less likely activated. Forty college-aged women were asked to read a mock research article that suggested a height-related growth hormone was related to risk of breast cancer. Half of the women received the article that suggested this risk was greater in women 5 ft. 4 in. and taller, whereas the other half read the article that suggested increased risk in women 5 ft. 4 in. and shorter. Perceived vulnerability was split into high and low groups based upon participants' self-reported height and the article version they received (Arndt et al., 2007). After completing filler personality measures and reading an assigned article, participants were given a survey to determine whether or not

they had understood the growth hormone article. Participants were then asked to rate how threatening the article was for them on a scale from 1 (*not at all*) to 9 (*very threatening*). Next, the death thought accessibility measure, identical to the one used in Study 1 and 2, was given. Last, a demographic questionnaire was provided in which participants reported their height. Results indicated that participants in the high vulnerability group showed lower death thought accessibility versus those in the low vulnerability group. Further, self-reported threat played a mediating role between vulnerability and death thought accessibility. In other words, participants who perceived themselves as vulnerable experienced increased perception of threat, which then led to increased suppression of death thoughts (made evident by lower death thought accessibility).

Study 5 extended the findings of Study 2 by exploring in a sample of undergraduates whether being able to suppress death-related thoughts after a cancer prime was related to intention to engage in health-related behaviors (Arndt et al., 2007). Participants were randomly assigned to a high or low cognitive load condition and primed to think about either cancer or asthma. Unlike the previous four studies, the dependent variable for Study 5 was participant intention to engage in a breast or testicular self-exam. Results showed that the hypotheses were supported. In the low cognitive load group, self-exam intentions were higher among participants primed with cancer than those primed with asthma. In the high cognitive load group, participants primed with cancer demonstrated lower intentions than the asthma group. As expected in the cancer condition, participants under high cognitive load reported lower intention for self-exams

than those under low cognitive load. However, no such differences were found in the asthma condition (Arndt et al.).

Limitations of the Arndt and colleagues (2007) studies were the varying priming techniques and outcome variables used to measure the constructs as well as the use of college student samples. Nevertheless, thought suppression was consistently found in all five studies. TMT researchers have maintained that mortality salience is the principal prime for activating death thought accessibility. However, results from Arndt and colleagues showed similar effects of cancer salient conditions, but only if the cancer primes occurred outside of consciousness through subliminal priming. The authors suggested that future studies should identify the ways in which priming effects of cancer engender the need for psychological defenses.

Findings from terror management studies suggest that even priming individuals in laboratory settings to imagine having cancer increases death-related thoughts under high cognitive load conditions (Arndt et al., 2007). This would suggest that recently diagnosed cancer patients might be particularly sensitive to death-related thoughts under the strains of deciding appropriate treatment options, work-related adjustments, and lifestyle changes that likely occur after a diagnosis. However, it is unknown if increases in death-related thoughts translate to vocalization of these thoughts. Based on findings from the Little and Sayers (2004) study, it could be argued that recently diagnosed cancer patients in the mortality salient phase might be more reluctant to discuss death because they are in the mode to fight cancer rather than dwell on the possibility of succumbing to the disease. It is possible that individuals in the death awareness phase may be more

willing to reflect on their experiences of death after the dust from the battle for survival has cleared.

Results yielded from by the Arndt and colleagues (2007) and Little and Sayers (2004) studies illustrate the psychological complexity of cancer due to the internal changes the patient may experience as he or she moves through treatment. These studies also demonstrate that cancer is a powerful primer for thoughts about one's own mortality. Although these findings provide important information about the psychological aspects of a cancer diagnosis, they also raise many more questions about the experience of living with cancer. For example, would the death awareness continuum proposed by Little and Sayers (2004) be found in a gender-specific cancer subpopulation such as individuals with gynecologic cancer? How might the data emerge without the constraint of predetermined categories? Because cancer has been shown to be a powerful primer for death-related thoughts (Arndt et al.), what specific types of psychological defenses would be utilized as a result of a cancer diagnosis? In order to address these unanswered questions, individual interviews were used in the present study to explore the existential experiences of women diagnosed with gynecologic cancer.

Qualitative Research

Qualitative research aims to “describe and clarify experience as it is lived and constituted in awareness” (Polkinghorne, 2005, p. 138) within a specific context. Qualitative researchers are “intrigued by the complexity of social interactions expressed in daily life and by the meanings that the participants themselves attribute to these interactions” (Marshall & Rossman, 2006, p. 2). In order to capture the rich layers of

complex human interactions and experiences, researchers must use “vertical depth” (Polkinghorne) or “thick” descriptions (Geertz, 1973). Thick descriptions include individual worldviews, feelings, thoughts, and intentions, situated within a context and revealed through participant language and observation rather than standard statistical procedures. A primary advantage of this approach over more traditional scientific research methods is that data are not confined by predetermined hypotheses, but rather are *discovered* through interactions between the researcher and the individuals to explore the phenomenon of interest. Further, qualitative methods allow intricate details and nuances of human experiences to be captured and brought to “public view” (Polkinghorne, p. 138).

The natural direction one might take to explain qualitative research is to compare and contrast it to quantitative research. However, because each method provides distinct and alternative scientific angles of understanding phenomena, comparing one to the other is neither constructive nor helpful. Nozick (1989) used photography and portrait painting as analogies to understand the unique contributions of both methods to scientific research (in Haverkamp, Morrow, & Ponterotto, 2005). Quantitative research is analogous to photography where the camera is meticulously adjusted and focused to capture a precise image of interest to the photographer. Qualitative research is the portrait painting created over time to reflect the likeness and depth of a subject; however, the final product will always reveal the distinct techniques of the painter regardless of the exactness of the portrait. In sum, photography and portrait painting demand great proficiency from the

photographer and painter as artists, as do qualitative and quantitative research from the investigators as scientists.

The basic questions of qualitative research are to understand how people co-create, manage, and interpret the world through their personal lens. Most often, answers to these questions are provided in transcribed conversations between the researcher and participant (Polkinghorne, 2005). Meanings from these conversations are interpreted not from the actual text, but the “evidence...[in] the ideas and thoughts that have been expressed by the participants” (Polkinghorne, p. 138), much like the subtle color shading and brushstrokes in portraiture. The purpose of the present study was to develop an understanding of the processes by which women with gynecologic cancer manage their death anxiety. From this understanding, the aim was to develop a theoretical framework of death anxiety management within the gynecologic cancer population.

Philosophical Paradigms

Science, according to Ponterotto’s (2005) broad definition, is “the systematic quest for knowledge” (p. 127). The way in which this quest for knowledge is approached is based upon the philosophical framework of science (Ponterotto). The philosophy of science used to understand a phenomenon is comprised of five scientific parameters: ontology, “the nature of reality and being” (Ponterotto, p. 127); epistemology, “the study and acquisition of knowledge, and the relationship between the knower [research participant] and would-be knower [the researcher]” (p. 127); axiology, “the role and place of value in the research process” (p. 127); rhetoric, “language and presentation of the research” (p. 127); and methodology, “the process and procedure of research” (p. 127).

Together, these scientific parameters provide the basis for a philosophical paradigm that, in turn, presents a framework in which to understand the phenomenon of interest in an orderly and systematic way (Strauss & Corbin, 1990).

Many philosophical movements have occurred in qualitative research, from positivistic to more modern interpretive paradigms, leaving a trail of paradigmatic offspring. Burrell and Morgan (1979) offer a structure composed of a subjective-objective continuum and radical change-regulation continuum to help organize the qualitative paradigms (or lens) through which the data will be transmitted based on the aims of the researcher. The subjective-objective continuum is based on how much value the researcher places on subjectivity or objectivity in investigating a research topic. Research located on the objective end of the continuum would involve positivist scientific methods such as systematic observations, theory, hypotheses, operational definitions, experimental conditions, and statistics to work towards the prediction of a phenomenon (Ponterotto, 2005). On the subjective end is research based on examining unique perspectives of the individual rather than attempting to uncover the ultimate “truth” (Ponterotto).

The radical change-regulation continuum is based on whether the researcher’s goal is to maintain or challenge the status quo (Burrell & Morgan, 1979; Ponterotto, 2005). Studies positioned on the radical change end would aim to understand structural relationships and social structures for emancipation and transformation purposes (Burrell & Morgan; Ponterotto). On the regulation end of the continuum are researchers who

would be more interested in providing descriptions or explanations for social interactions than promoting direct change within the population of interest (Burrell & Morgan).

The crossroads of the subjective-objective continuum and radical change-regulation continuum give way to four main paradigms, characterized by the position in which they fall on the continua. The radical humanist and radical structuralist paradigms are characterized by change; however, humanists value subjectivity whereas structuralists value objectivity. The functionalist (or positivist) and interpretive paradigms emphasize regulation; the two paradigms differ in that functionalists favor objectivity and interpretivists favor subjectivity. The present study is located in the interpretive paradigm. The essence of interpretivism is that reality is created in the mind of the individual (Hansen, 2004) and thus, hidden. The way to bring forth this hidden meaning is through deep reflection (Schwandt, 1994), which can be stimulated by the interactive researcher-participant dialogue. Through this interpersonal interaction, meaning can be uncovered and findings can be co-created.

For this study, the interpretive paradigm was used as the lens in which to understand the phenomenology of death anxiety in women with gynecologic cancer. This paradigm was most fitting because as the goal was to understand the death-related thoughts and feelings of these women in order to learn how they manage and make sense of an existential crisis such as cancer. This study is located on the subjective end of the continuum because it was assumed that each participant would contribute a unique story about her gynecologic cancer experience. The goal of a more subjectively-oriented paradigm is not to uncover a singular “truth.” Rather, it is to describe the experiences of

participants as those experiences are lived. Thus, the present study is situated on the regulation end of the continuum.

Grounded Theory

Grounded theory, a type of qualitative approach, is “one that is inductively derived from the study of the phenomenon it represents” (Strauss & Corbin, 1990, p. 23). Developed in 1967 by Barney Glaser and Anselm Strauss, grounded theory is used to explore a general research question by identifying core concepts, creating conceptual categories, identifying relationship patterns among concepts, and developing explanations through the research process (Charmaz, 2006). Grounded theory does not simply provide descriptions of a lived experience; this approach attempts to produce a theory grounded in participant language based on participants’ interactions with the world around them (Creswell, 2007). The goal is then to shed light on a phenomenon through systematically and inductively derived theory and to test it in future studies. As with any other scientific approach to investigating a research question, qualitative research has its own sets of criteria for evaluating scientific rigor. Although qualitative approaches differ conceptually from quantitative methods, the basic guidelines of “good” science are still upheld. These methods, also known as rigor and trustworthiness, will be discussed in more detail in the “threats to trustworthiness” section.

Since its conception, several variants of grounded theory have emerged (Strauss & Corbin, 1990). Therefore, the qualitative researcher must be comfortable with the idea that a standard guideline for conducting qualitative research does not exist. Because “the *very idea* of qualitative research is open to question” (Rolfe, 2006, p. 305), attempting to

force qualitative research under a single paradigm would be contrary to its philosophical underpinnings. Rolfe stated that rather than viewing one framework as *the way*, researchers should recognize and embrace the contributions of each qualitative paradigm in understanding phenomena. In the same vein, a grounded theory approach may fall under several philosophical paradigms contingent upon the scientific parameters on which it was created (Ponterotto, 2005).

One of the most prominent grounded theory approaches belongs to Charmaz (2006). This comprehensive approach includes contextual factors, social relationships, and individual worldviews in understanding the phenomenon of interest. This is markedly different from “classic” grounded theory, in that the researcher takes contextual factors into account rather than attempting to uncover a single core process to explain a phenomenon (i.e., “truth”). Further, whereas classic theorists adopted a more positivistic view in that “truth” can be known and uncovered in participant language, Charmaz (2006) argues for an “interpretive” focus. This focus is on building an understanding of a phenomenon, anchored in context versus creating testable hypotheses. As a result, the aim is to eliminate a “one-size fits all” methodological approach for a greater emphasis on the pursuit for meaning. In other words, “‘truth’ is no longer the goal of the research process and product” (O’Conner, Netting, & Thomas, 2008, p. 30).

Grounded theory, in large part, falls under the interpretive paradigm. Ontologically, this approach maintains that multiple realities exist and are co-created as a result of interactions with the world around us, contrasting with the positivist and postpositivist assumption that a single objective reality exists and can be discovered

through tightly regulated experimental studies. The epistemological view of grounded theory comes from investigating the lived experience (*Erlebnis*) of the participants.

Through close interactions between the researcher and participants, mainly via individual face-to-face interview, these lived experiences can be understood and interpreted. From an axiological standpoint, grounded theorists generally acknowledge and explicate their biases and expectations in their research. From a rhetoric standpoint, grounded theory studies are written in the first person and generally aim to lend participants a “voice” by using specific participant quotes generated through the interview process.

Methodologically, grounded theory studies typically gather in-depth information through face-to-face individual interviews, clarification of spoken words, and use of a working semi-structured interview guide based on participant direction (Ponterotto, 2005).

Research Question

The ways in which individuals manage death anxiety have been extensively tested and supported through experimental methods (e.g., Pyszczynski et al., 2003). However, little is known about how women with gynecologic cancer manage the existential predicaments inevitably brought forth by their diagnosis. The present study is one of the first to venture into this unknown territory.

Regarding the target population, this cancer population was specifically chosen for several reasons. First, the gynecologic cancer literature is relatively sparse. Second, gynecologic cancer research in general tends to focus more on relevant but symptomatic consequences of a gynecologic cancer diagnosis, such as sexual dysfunction and quality of life, rather than exploring the psychological processes that occur when a woman has

been given a diagnosis that *threatens her very existence*. Last, gynecologic cancer is unique to females and as a result, women with this type of cancer may experience literal threats to mortality as well as *symbolic* threats to womanhood subsequent to an excision of a reproductive organ.

Qualitative methods were used to capture the nuances of the cancer experience without the constraint of hypotheses. Moreover, this method allowed for participant language to inform the principle theoretical components of this developing research area by approaching participants as the “experts” in the gynecologic cancer experience (Anderson & Goolishian, 1992). This type of method also permitted topics of sensitivity to be explored (Padgett, 1998), such as death. Data collection and analysis were informed by Charmaz’s (2006) interpretive paradigm.

The overarching research question was “What are the experiences and processes by which women with gynecologic cancer construct meaning and manage death anxiety in the face of their cancer diagnosis?” The interview questions, which helped to guide the researcher in understanding the gynecologic cancer experience, are discussed in Chapter Three.

CHAPTER THREE

Method

Research Design

The research design of the proposed study was based on an interpretive paradigm. Thus, the methodology of this study reflected the ontological, epistemological, and axiological stances as described in Chapter Two. Because of this paradigm's focus on researcher-participant dialogue as a way to uncover hidden meaning imbedded in language, individual face-to-face interviewing and participant observation were used to gather information. To gather "thick" descriptions of participants' experiences, open-ended questions were used to understand the function of interpersonal relationships and the cultural and historical contexts in which the participant lives.

Grounded theory techniques based on Charmaz (2006) were applied to analyze and interpret data. These techniques will be elaborated in a later section. Specific procedures were put into place in order to enhance the trustworthiness (i.e., scientific rigor) of the present study, particularly because the interpretive paradigm emphasizes the role of the researcher in the research process. This chapter contains the procedures by which research subjectivity was addressed to ensure that participants' viewpoints and perceptions of the gynecologic cancer experience were accurately depicted.

Through individual face-to-face intensive interviews (Charmaz, 2006), the gynecologic cancer "experience" of each participant was captured to allow understanding

of the experience as it is lived. The “processes” of participants were understood through their thoughts, feelings, and behaviors that have helped them manage a potentially fatal disease.

Role of the Researcher

The role of the researcher was that of the interviewer. The interviewer’s role was to develop rapport with the participants, show warmth and respect, demonstrate empathy, and ask questions pertaining only to the present research study. This role, consistent with the relativist position of the interpretive paradigm that there are multiple realities co-created through human interactions and shaped by contextual factors, was an interactive one designed to pursue an emic perspective. This perspective is defined as “the constructs or behaviors that are unique to an individual, sociocultural context that are not generalizable” (Ponterotto, 2005, p. 128). Participants recruited for qualitative studies can be referred to as conversational partners in that both the researcher and participant were fully engaged in conversation to understand in-depth the phenomenon explored.

Participants

Women considered eligible for the study (1) were 18 years or older in age, (2) were fluent in spoken English, (3) had been clinically diagnosed with Stage I-IV gynecologic malignancy (i.e., cervical, ovarian, or uterine/endometrial cancer), (4) had received at least one treatment procedure (e.g., chemotherapy) but not finished treatment, (5) had been diagnosed within the last 2 years, and (6) were not considered imminently dying by their physician.

Criteria 4 and 5 were based on studies that suggested death anxiety levels might vary depending on time since diagnosis rather than disease stage or cancer type. For example, death anxiety in patients less than 2 years post diagnosis was greater than in those 5 years post diagnosis (Cella & Tross, 1987; Sigal et al., 2008). This parallels findings that quality of life in gynecologic cancer survivors returns to that of healthy controls 5 years after diagnosis (Bradley et al., 2006). Criterion 6 was based on research that suggests that end-of-life patients may report qualitatively different experiences than patients who are not terminally ill (e.g., Sigal et al). In addition, nursing staff were consulted before meeting a potential participant to ensure that the patient did not meet any exclusion criteria: (1) a current psychotic disorder, (2) a current suicidal intent/plan, and (3) any cognitive deficits that might impede the interview process.

Data Collection Procedures

Purposeful or purposive sampling (Bogdan & Biklen, 2007; Charmaz, 2006; Morrow, 2005) was used to recruit participants. According to Morrow, this is when “participants are deliberately selected to provide the most information-rich data possible” (p. 255). For this study, women with gynecologic cancer were recruited because it was assumed that they would be rich in information about the gynecologic cancer experience. Information-rich cases allowed for in-depth study of the phenomenon of interest rather than the use of data to transfer results to other populations. Consistent with the grounded theory technique of achieving timely data saturation, or when no new information is collected from participants, a cohesive sample was chosen based on specific characteristics associated with the gynecologic cancer experience (i.e., time since

diagnosis and stage of treatment). Although there are no clear guidelines to the number of participants required for data saturation, this can occur with anywhere from 6 (Morse, 1994) to 12 participants (Morrow, 2005). The expected sample size for the present study was 8 to 12 participants, and the actual sample size was 10.

Participants were recruited from an urban cancer center because the location allows for greater patient accessibility for face-to-face individual interviews. Further, greater accessibility allowed for opportunities for participant follow-up when data needed to be clarified or elaborated (i.e., member checking). Approval from the Institutional Review Board was secured before starting recruitment. In addition, an attending physician in the Department of Obstetrics and Gynecology was consulted prior to recruitment to determine the feasibility of recruiting women based on specific study criteria.

Collection of data began August 2008 and ended December 2008. The researcher attended Wednesday morning clinic days at an urban medical center and identified eligible participants with the assistance of attending physicians and nurses. The researcher continuously interacted with the data and began to identify themes throughout the recruitment process, consistent with Charmaz's (2006) interpretive framework. Participants were recruited to participate in an individual face-to-face interview to capture the "lived experience" of the participant through dynamic interaction. This data collection method was consistent with the interpretive epistemologic stance.

During the introductory meeting with the participant, a detailed explanation of the study was provided as well as the consent form (see Appendix B). Informed consent was

obtained before conducting any interviews. In addition, this investigator gathered demographic information through a brief survey. Such information included age, ethnicity, date of birth, time since diagnosis, type of cancer, and type of treatment (see Appendix A).

Semi-structured interviews were conducted. These interviews were loosely structured and consisted of several open-ended questions. The loose structure was designed to keep the focus on a specific topic yet allow the researcher and participant to deviate into other related areas (Britten, 2000). Interviews were audio recorded and conducted in private clinic rooms, during waiting periods or during treatment. During the interview, the researcher consulted an interview guide (see Appendix C) to ask open-ended questions to facilitate participant responses. Open-ended questions were used to allow participants to describe their experiences. Field notes were also taken about the setting, seating arrangements of the interviewer and participant, and any remarkable occurrences (e.g., laughing). Field notes were brief and minimal to avoid disturbing the flow of conversation between the researcher and participant. This type of data collection method is particularly valuable in qualitative research because it allows for the natural unfolding of the participant's perspectives about the phenomenon of interest. In addition, interviewing allows for in-depth information, observation, and immediate follow-up and clarification of participant language. Open-ended questioning is also consistent with the interpretive paradigm in that it fosters unique and personal worldviews of the participants to be brought forth.

The general research question was, “What are the experiences and processes by which women with gynecologic cancer construct meaning and manage death anxiety in the face of their cancer diagnosis?” The first interview question was, “What were your first thoughts on hearing your cancer diagnosis?”

Although this first question did not directly address death anxiety, research shows that patients, even when they are first diagnosed, are immediately confronted with thoughts about their own mortality (e.g., Little, Jordens, Paul, Montgomery, & Philipson, 1998). With participants for whom this subject area did not naturally arise in the beginning of the interview, a specific question was asked in order to address their understanding of it: “Some people have said that after they are diagnosed with cancer, they immediately think about the possibility of their own death. Does this fit with your experience?” Questions were altered during data collection to gather more relevant data (for a list of interview questions for each participant, see Appendix F). Minimal probes and prompts were used to guide the interview process and clarify the meaning of participant language.

The researcher took several steps to ensure that the interview was conducted appropriately. Before the interview, participants were assured that field notes would not contain any identifying information and that all tapes would be destroyed at the end of the study. In addition, the importance of the data given by the participant was discussed and how the information would be disseminated appropriately within the academic community. After the interview, each participant was thanked and asked if she would be willing to share her contact information. The purpose of obtaining contact information

was so that the researcher could contact the participant for any follow-up questions. Last, each participant was given the investigator's contact information should she have any further questions. This comprehensive exit strategy allowed for participant involvement and contribution in order to help eliminate potential feelings of exploitation or abandonment (Marshall & Rossman, 2006).

Axiology undergirding the interpretive paradigm assumes that researcher bias cannot be separated from the research process, particularly given the interpretive epistemological stance of staying in prolonged contact with participants. Rather than attempting to eliminate researcher biases, the researcher should instead acknowledge and "bracket" personal values through auditing. The recruitment and data collection processes were tracked by leaving an "audit trail" in order to make transparent the "actual course of the research process rather than the *idealized* version that the reader is usually presented with" (Rolfe, 2006, p. 309). This audit trail (see Appendix E) involved keeping a detailed reflexive research journal to record personal feelings, thoughts, and biases that could be "examined and set aside to a certain extent or consciously incorporated into the analysis, depending on the frame of the researcher" (Morrow, 2005, p. 254).

A separate methodological journal was used to record specific changes or variations to procedures that have occurred during the research process. Follow-up phone calls were made to participants to give them an opportunity to comment on the themes and categories identified during data analysis. In sum, the reflexive and methodological journals coupled with the follow-up interviews contributed to the rigor of

the present study through triangulation (i.e., multiple data sources). These additional data collection strategies were considered secondary data sources to help reduce researcher subjectivity (Morrow). Threats to rigor and ways to minimize these threats are discussed more in detail in a later section.

Data Analysis

Consistent with common grounded theory techniques, interviews were transcribed and coded after they are conducted to identify salient themes and pattern consistency. *Verstehen* or understanding the meaning behind participant language (Kaufman, 2004; Patton, 2002) was achieved by using grounded theory techniques to analyze data in addition to asking participants to clarify or elaborate their spoken words. Consistent with the concept of *verstehen* is that the researcher must acknowledge that categories that emerge through inductive data analysis are the result of the interpersonal interactions between the researcher and participants (Charmaz, 2006). Therefore, predetermined concepts must not be forced upon themes that emerge from the data (Charmaz). The literature shows that grounded theorists diverge on techniques that facilitate or hinder *verstehen* (Morrow, 2005); thus, the researcher created an audit trail to track the techniques utilized in the present study.

A rule of thumb that was followed during data analysis is to “give all data equal consideration in the analytic coding procedures” (Morse, 1995, p. 147). A unique aspect to qualitative data analysis is that outliers in the data are not eliminated or mathematically manipulated as they are in more traditional methods of analysis. Rather, in qualitative research, outliers are considered the “infrequent gem that puts other data into perspective

that becomes the central key to understanding the data and for developing the model. It is the *implicit* that is interesting” (Morse, p. 148). It is important to have thick and rich data descriptions to begin building a cohesive theory. Thick and rich data are elicited through detailed descriptions of participants’ actions, records of “observations that reveal participants’ unstated intentions,” interview questions that facilitate participant reflection (i.e., open-ended questions), and examining “taken-for granted meanings and actions” (Charmaz, 2003, p. 88).

In the present study, all interview data were transcribed within 48 hours of the interview. Transcripts were read through several times in order to pick out salient themes among the data. In addition, after the initial read through, the researcher wrote down immediate thoughts or reactions in the reflexive journal. Emergent themes were evaluated repeatedly in order to examine the consistency of the patterns. Themes were then systematically coded and organized to identify overlapping and discrepant concepts within all the interviews. Standard qualitative analytic methods were used under the “constant comparative” (Glaser & Strauss, 1967) umbrella, meaning data were compared with each other for common themes or differences. Four main grounded theory techniques were used to analyze the data: (1) line-by-line coding, (2) focused coding, (3) memo writing, and (4) theoretical sampling (Charmaz, 2006).

In line-by-line coding, each line of data was examined and numbered to identify embedded actions or events within it (Charmaz, 2006). This allowed the researcher to take an “analytic stance” to the data and guided the way toward building theoretical categories. Further, it helped to prevent the researcher from imposing personal ideas onto

the data and coloring the interpretation process (Charmaz, 2003). Charmaz (2003) recommends naming codes in concise, specific terms to help identify the processes that emerge from the data and to help the researcher critically examine the data at hand. Line-by-line coding also facilitated this investigator in deciding what kinds of data to collect in the next interview. After the first read-through, 111 initial codes were found. Transcripts were read through a second time in order to identify codes that may have been missed during the first read-through. Overlapping codes were then collapsed into smaller ones; these codes were then used for the next analytic step.

After developing initial codes through line-by-line coding, this investigator used focused coding, or “selective” coding, to sort through larger amounts of data using the existing codes (Charmaz, 2003). Overlapping and discrepant concepts within the interviews were identified by examining the conceptual themes and categories that emerged. This coding step was also used to integrate the data, reassess existing codes, and refine definitions and concept patterns. Each coding process informed the next interview (e.g., modifying the guiding questions), allowing the participants’ language to guide the research process. This coding technique called for the researcher to decide which codes “make the most analytic sense” (Charmaz, 2003). Because this process was not a linear one, continuous coding led the researcher to understand implicit meaning hidden in earlier interviews. Earlier interviews were then reexamined for any significant categories that were originally missed. Focused coding propels the data analysis process “to establish the content and form of [the] nascent analysis” and “to evaluate and clarify [the] categories and relationships between them” (Charmaz, 2003, p. 99). Through the

use of categories, this researcher was able to “explicate ideas, events, or processes in [the] data” (Charmaz, p. 99).

Memo-writing is an important data interpretation technique and the “pivotal intermediate step between defining categories and the first draft of [the] completed analysis” (Charmaz, 2003, p. 102). This technique encouraged this researcher to expand upon the “processes, assumptions, and actions” defined by the codes and categories that emerged from the data (Charmaz, p. 102). In addition, memo-writing assisted in classifying codes that were used as analytic categories, further developing categories, and obtaining empirical evidence (i.e., transcriptions) to support developed categories and interpretations (Charmaz).

During and after the memo-writing phase, data were continuously organized and rearranged by printing out transcripts on different colored sheets of paper, selecting specific quotes, and sorting these quotes into relevant categories. (For a list of the categories and subcategories, see Table 2.) The iterative nature of qualitative research required that the researcher reread each transcript, refine the definition of categories, and compare and contrast transcripts. The categories and subcategories were continuously revised and refined throughout the data analysis process.

In addition to the aforementioned techniques of grounded theory, theoretical sampling was used to address any questions or gaps that the memo-writing process raised and help build a cohesive theory grounded in the data. This sampling technique, conducted via follow-up phone calls to the participants, was used to build upon the budding theory and strengthen the fit between data and theory, *not* to increase generalizability. Taking into

account Charmaz's (2003) caution that theoretical sampling conducted early on the research process may "bring premature closure to [the] analysis" (p. 106), this process was carried out after the 10 interviews were conducted to avoid any theoretical holes. This process is further elaborated in a later section.

Threats to Trustworthiness.

Trustworthiness, or rigor, of a qualitative study requires specific steps in order to adhere to good scientific practices. Similar to traditional quantitative methods of scientific inquiry, trustworthiness is categorized into credibility (internal validity), dependability (reliability), transferability (external validity), and confirmability (objectivity). As noted earlier, trustworthiness can be further bolstered through auditability or "a decision trail" to track and verify the research process (Rolfe, 2006; Sandelowski, 1986). Credibility (Sandelowski, 1998), or what the participants stated in their interviews, was addressed by mechanically recording data through the use of a tape recorder to capture participants' gynecologic cancer experience verbatim. In addition, any "negative cases" or discrepant data were examined and configured with common categories to shape the interpretation of data. Moreover, theoretical sampling allowed the researcher to check the validity of categories and deepen understanding of emerging categories. Dependability was achieved through the use of an interview guide so that interviews are conducted in a consistent manner. Transferability is less of an issue in qualitative research because qualitative researchers seldom attempt to generalize their findings (Holloway, 1997). However, in the present study, implications for future studies to be conducted in other cancer populations are given in Chapter Three. Confirmability,

“based on the acknowledgment that research is never objective” (Morrow, 2005, p. 252), was addressed through the use of an audit trail to manage subjectivity.

Though specific data analytic techniques (e.g., line-by-line coding) were in place to limit bias, a threat to trustworthiness, human factors inevitably played into the data analysis and interpretation process. Therefore, to help limit bias, two graduate student auditors were employed so the researcher would receive feedback from those outside of the study to help clarify areas this investigator may have overlooked. These auditors have a background in research methodology. Further, one auditor had conducted a cancer-related phenomenological study for her thesis prior to the auditing process, which allowed her to be familiar with managing transcript data. The auditors checked for coding accuracy and consistency by providing spot checks to help this investigator track the decision-making process during data analysis. The auditors were involved mainly during data analysis to check for coding consistency and for potentially missed codes. Using a random number generator, each auditor was assigned five different interviews and asked to incorporate the following questions during the auditing process: (1) Do the categories and themes seem to represent the participants’ descriptions?, (2) Do the data seem to fit the categories?, and (3) Do the descriptions of the phenomenon capture the themes identified and the content of the transcripts? Auditors were then asked to provide feedback on the degree of fit they perceived between the data and constructed categories. One auditor noted no disagreement with the researcher’s categories and subcategories. The other suggested adding in a minor change to the definition of *emotion-focused*

reaction, a subcategory. Fully agreeing with this suggestion, the researcher redefined this subcategory to distinguish it from the subcategory of *religion*.

As part of theoretical sampling to assess the fit between the researcher's categories and participant data, each participant was contacted by phone to give them the opportunity to respond to the categories (see Appendix D for the phone script). All but one participant had agreed to give their contact information for follow-up. Prior to this follow-up phone call, the nurses who had assisted with recruitment were contacted to determine the health status of the participants. The nurses informed the researcher that two of the participants had died during the course of the study and that one was currently in hospice care. Of the six participants whom the researcher attempted to contact, three were reached and indicated that they agreed with the findings of the researcher.

In qualitative research, researcher subjectivity is an important area to be addressed to ensure trustworthiness of the study (Morrow, 2005). Researcher subjectivity encompasses personal biases and ideologies about the world and how these assumptions will interact with the data to color analytic process. To counter these effects, the researcher documented thought processes, feelings, and assumptions in a reflexive journal throughout the research process. In addition, the researcher viewed the participants as the "experts" of the gynecologic cancer experience (Anderson & Goolishian, 1992) to avoid imposing personal opinions onto the phenomenon of interest. Because subjectivity is present in all types of research, it is the responsibility of the researcher to acknowledge and make these areas as transparent as possible to help offset potentially negative effects on the data collection and analysis processes (Morrow).

Although the reflexive journal was used to counter any negative effects of personal subjectivity in interpreting the data, the rhetoric used in the discussion chapter reflects the epistemological and axiological stance of the interpretive paradigm. This means that Chapter Five was written in the first person and personalized to demonstrate this investigator's interactive role in the study. Chapter Five also documents the researcher's personal experiences, expectations, and values in an open and reflective manner.

Summary

In summary, the present study employed grounded theory techniques from an interpretive perspective to gather, analyze, and interpret data. The primary method of data collection was through individual interviews in a closed setting. Researcher subjectivity was addressed by making personal thought processes transparent through a reflexive journal. Theoretical sampling was used to ensure accuracy of the meaning behind participant language. Further, an audit trail illuminated any changes that occurred throughout the research process to maintain trustworthiness or validity of the present study. By using a grounded theory framework and data techniques, the researcher constructed a theory on the processes by which women with gynecologic cancer manage their death anxiety in light of their diagnosis. Further, investigating the existential experiences of these women allowed deeper understanding of the ways in which individuals managed the inevitability of death and how these processes subsequently affect their lives (Yalom, 1980).

CHAPTER FOUR

Study Findings

Findings generated from this study are categorized into five main categories and eight subcategories. To delineate these findings, this chapter is divided into several sections. First, an overview of the sample and a brief summary of each participant are presented. Second, a description of findings is presented in addition to a visual table of these findings. The next sections summarize the categories and subcategories that emerged from the data. These sections attempt to answer the primary research question: What are the ways in which women with gynecologic cancer manage death anxiety in relation to their diagnosis?

Description of Sample

A total of 10 women participated in the present study. Women considered eligible for the study (1) were 18 years or older in age, (2) were fluent in spoken English, (3) had been clinically diagnosed with Stage I-IV gynecologic malignancy (i.e., cervical, ovarian, or uterine/endometrial cancer), (4) had received at least one treatment procedure (e.g., chemotherapy) but not finished treatment, (5) had been diagnosed within the last 2 years, and (6) were not considered imminently dying by their physician. Selected demographic characteristics of the participants are summarized in Table 1.

The mean age of participants was 63.2 years ($SD = 12.16$), ranging from 39 to 80. Six of the 10 women described their race as White or Caucasian, whereas the remaining

four participants self-identified as Black or African American. Out of the 10 participants, five had received at least some college education, four had received high school diplomas, and one had received an 8th grade education or less. All of the women indicated that they had a religious or spiritual affiliation. There was diversity in cancer diagnosis, stage, and treatment. Three participants were diagnosed with gynecologic cancer in 2008, five in 2007, and two in 2006. Regarding specific cancer diagnosis, half of the participants were diagnosed with ovarian cancer and the other half diagnosed with endometrial/uterine cancer. Of the eight participants who identified their cancer stage, staging ranged from Stage I to IV. Eight participants had undergone surgery and were receiving chemotherapy at the time of the interviews. Of the 10 participants, two indicated that they had experienced a previous cancer diagnosis unrelated to their current diagnosis.

Participant Summaries

Lula. “Lula”¹ is a 66-year old, Caucasian female. After being treated for breast cancer several years ago, she was diagnosed with Stage I ovarian cancer in 2007. She travels to the medical center to receive chemotherapy. Lula described her ethnicity as American and identifies as Methodist. She is a high school graduate and has been retired since 2006. She is divorced and has an adult child who is 36 years of age. None of Lula’s family members have had cancer.

¹ All participant names are pseudonyms for confidentiality purposes.

Lily. “Lily” is a 59-year old, Caucasian female. She was diagnosed with Stage II endometrial cancer in 2007. After undergoing surgery, she is currently receiving chemotherapy. She has a family history of cancer, including her father who was diagnosed with colon cancer. Lily self-identifies as Catholic. She has received some college education but did not complete her degree. She is married and has a son and daughter, both in their mid to late 30s. Lily is currently on disability.

Lucille. “Lucille,” the oldest participant, is an 80-year old, Caucasian female. She was diagnosed with Stage IV ovarian cancer in 2008. She described her ethnicity as American and her religious affiliation as Baptist. Lucille initially underwent surgery after her diagnosis and currently receives chemotherapy. She has an extensive family history of cancer, including both of her parents, her niece, and her nephew. A high school graduate, she has been retired since 1975. She has a 54-year old daughter and is a widow. Lucille lives with her daughter and son-in-law and is eager to return to her own home to regain independence.

Susie. “Susie” is a 77-year old, Caucasian female diagnosed with Stage III ovarian cancer in 2008. She initially underwent surgery and now receives chemotherapy. In addition to her personal battles with breast cancer and melanoma, Susie experienced the loss of her father, sister, and husband to cancer. She identifies ethnically as American and describes her religious beliefs as Lutheran. Susie has received some college education. She is widowed and does not have any children. She has been retired since 1983.

Molly. “Molly” is a 61-year old, Caucasian female who was diagnosed with Stage III ovarian cancer in 2007. She underwent surgery and currently receives chemotherapy. She has not had a previous cancer diagnosis nor does she have a family history of cancer. Molly self identifies as Protestant. She has received her high school diploma and is currently on disability. She is widowed and has adult children, ages 35, 43, and 44.

Faith. “Faith” is a 51-year old, African American female, diagnosed with ovarian cancer in 2007. After undergoing surgery, she now receives chemotherapy. Faith has not had a previous cancer diagnosis or a family history of cancer. She describes her religious affiliation as Baptist. She is a college graduate and on disability. Faith is married and has a daughter, 28, and a son, 18.

Jennifer. “Jennifer”, the youngest participant, is a 39-year old, African American female. She was diagnosed with endometrial cancer in 2006. She initially underwent surgery and now receives chemotherapy. She has not had a previous cancer diagnosis. Jennifer identifies herself ethnically as American and her religious beliefs as Christian. She is a college graduate, married, and does not have any children. She is either on disability or applying for disability. Although she does not have a family history of cancer, Jennifer has been in a caretaking role for her mother and mother-in-law, both of who have experienced physical disabilities.

Susan. “Susan” is a 71-year old, African American female diagnosed with Stage IV endometrial cancer in 2007. She currently receives chemotherapy. She has not had a previous cancer diagnosis, but has a family history of cancer. Susan identifies herself ethnically as African American and describes her religious affiliation as Baptist. She

earned her high school diploma and worked as a custodial worker before retiring in 2003. She is widowed and has adult children, ranging in age from 40 to 51. Her eldest daughter suffered from a heart condition and died in October 2008.

Jean. “Jean” is a 68-year old, African American female diagnosed with Stage I endometrial cancer in 2008. She initially underwent surgery and now receives chemotherapy. She has not had a previous cancer diagnosis but has an extensive family history of cancer, which includes her own daughter, sister, and aunt. Jean identifies herself ethnically as Negro and described her religious affiliation as Baptist. She completed 8th grade and has been retired since 1998. She is married and has eight children, ranging in age from 43 to 55. A native New Yorker, she finds Richmond less than exciting.

Rebecca. “Rebecca” is a 60-year old, Caucasian female diagnosed with Stage III endometrial cancer in 2006. She describes her ethnicity as American and her religious affiliation as Episcopalian. She initially underwent surgery and now receives chemotherapy. She has not had a previous cancer diagnosis and is uncertain of her family’s history of cancer, believing her grandmother may have been diagnosed. Rebecca, who has completed some post-graduate education, still works as a realtor and enjoys her job. She is married and has a 31-year old daughter. She has made significant changes to her diet as a way to exclude processed, refined foods and include organic and whole foods.

Description of Findings

The initial coding process resulted in 111 codes. To help narrow down the number of codes to main categories and subcategories, codes that were not directly related to the research questions were eliminated or collapsed into a larger, overarching category. The technique of memo-writing was utilized in order to define and delineate the final 13 categories and subcategories, resulting in a theoretical conceptualization of how women with gynecologic cancer manage death anxiety.

Analysis of the data yielded five main categories and eight subcategories that described the processes by which women with gynecologic cancer managed death anxiety as a result of their diagnosis (see Table 2). Due to the nature of qualitative inquiry, rich information pertaining to areas unrelated to death anxiety was also gathered; however, given that these experiences were not directly linked to the research question, these findings were excluded from the analysis process (e.g., managing treatment side effects, relationships with medical staff, and the process of rehabilitation).

Cancer as a Reminder of Mortality

The first main category reflects how receiving a cancer diagnosis served as a reminder of one's own mortality. All 10 participants reported experiencing thoughts related to awareness of their own mortality as a result of cancer. Variations among these experiences included differences in when thoughts about one's own death became conscious, the frequency with which these thoughts arose, and how the women reacted to these thoughts about death. Some participants noticed having thoughts about mortality soon after diagnosis, whereas others experienced these thoughts well into their treatment

regimen. However, unlike the concept of a life instinct or *self-preservation*, the next category discussed, which encompasses thoughts and feelings that occurred immediately after participants were given their diagnosis, it appears that thinking about mortality is also a largely unconscious process.

Participants also differed in the frequency of death-related thoughts after their cancer diagnosis. Several women experienced an increase in frequency of thoughts related to mortality. Conversely, other participants noted that although they had had thoughts about their death after cancer diagnosis, the frequency with which they experienced these thoughts did not differ from what they experienced prior to cancer.

Molly, who was diagnosed with Stage III ovarian cancer in 2007, was one of the participants who did not experience increased thoughts about death due to her diagnosis.

She described her feelings:

I do not think of death any more often since I've been diagnosed with cancer. It's just the way that I feel, you know? I just—everybody's gotta go sometime so when my time comes, whether it's cancer or whether it's heart attack, accident, whatever then I'm ready. But the cancer—being diagnosed with cancer has not made me really think about death more than usual. . . .It did make me . . .get my living will in order because you don't know with cancer or with anything when your time's comin', but other than that I haven't had any thoughts on death more than usual.²

Susan, like Molly, did not experience thoughts about death in greater frequency after cancer. She attributed this to having faith that God would heal her and that the strength of her faith would be enough to carry her through the illness and allow her to survive.

² Extraneous words such as “um,” “uh,” “you know,” and “like” have been removed from participant quotes.

The remaining participants acknowledged they had had thoughts about their own death before cancer, but noticed an increase in their awareness of their own mortality after their diagnosis. For two of the participants, death as a potential reality came quickly after receiving their diagnosis. Faith, one of the two participants, remembered thinking that death was imminent until given a reality check by family members:

I guess you—the first thing you think of is, “I’m a die the next day or two or three days later. That’s it.” But when I went home...my aunts and all were there and she said, “You not gonna die tomorrow!” Until somebody says that to you, snaps you out of it, I think you live in that thought...

The second participant, Susie, who had been previously diagnosed with melanoma and breast cancer several years earlier, recalled her own fear of imminent death:

I didn’t expect to pull through this last one, the peritoneal because a friend of mine had gotten the information off the Internet and if you’ve read it, it’s not good at all. And I really didn’t think I would come home. I kinda thought I might even die on the operating table, which they said I could have, you know.

The concept of death was largely out of consciousness for most participants and to receive a diagnosis of cancer was a jolting experience, regardless of whether an individual had been diagnosed with cancer before. Rebecca, a first time cancer patient, described how cancer became an unexpected visitor in her world and how she was forced to acknowledge that she was not immune to sickness or death:

...I had been so healthy...I’ve had a lot of success and things that I’ve accomplished so to have something like that, like I said, that just doesn’t happen to me. Good things happen to me...my whole life, good things have happened to me. ... I think we all think we’re infallible, that we’ll be around forever.

The majority of the women responded to thoughts about their mortality by consciously attempting to avoid or buffer them through distraction, praying, or thinking

about the positive aspects of their lives. These methods, for the most part, allowed death-related thoughts to be pushed out of consciousness; however, certain events such as hearing about an acquaintance's death due to cancer, experiencing severe side effects from chemotherapy, and seeing other cancer patients grow sicker as a result of their disease served as subsequent reminders of death. Lily described a personal trigger for her:

But that's the main thing that really brought the mortality thing the most 'cause I kept thinking people with cancer just keep dragging it out until they weaker and sicker and weaker and sicker and I see the people in here [at Massey] look pretty bad.

Hearing about the death of an acquaintance with cancer also served as a chilling reminder of mortality and death for some participants. Lucille noted that the reality of death grew stronger if the acquaintance had been similar in her gender and age.

Self-preservation

The second main category is *self-preservation*. This category illustrates the innate human instinct to live after receiving potentially life threatening news (i.e., cancer diagnosis). Faith's initial reaction to her cancer diagnosis is a clear example of the concept of self-preservation: "I said, 'Oh no, hell no. You mistaken, you talkin' about somebody else. No way. You gotta show me.'" The data found in this main category were divided into two subcategories based on the ways in which individuals typically reacted in order to preserve life and minimize (i.e., remove from consciousness) thoughts about one's own death. The word "reaction" was used based on its definitions as "a response to some treatment, situation, or stimulus" and "an action induced by vital resistance to another action" (Merriam-Webster OnLine, 2009). Further, in this study,

task-oriented and emotion-based reactions are temporally distinct from the category of “managing awareness of one’s own mortality.” Participants typically spoke of these reactions as occurring soon after receiving a cancer diagnosis, whereas the actions defined by the category of “managing awareness of one’s own mortality” occurred throughout the cancer experience.

The first subcategory, *task-oriented reaction*, is defined as immediately focusing on the concrete and tangible aspects of managing cancer following a cancer diagnosis.

Being able to manipulate these tangible aspects allowed participants to perceive themselves as having control, increase their chances of survival, and distract themselves from the severity of having cancer. Participants reported organizing paperwork (e.g., living will), gathering information on cancer, and creating treatment-related task lists.

Emotion-based reaction, the second subcategory, is identified as immediately focusing on the internal arousal of specific feelings and emotions following a cancer diagnosis.

Participants reported sensing gut-level feelings and the urge to gather emotional strength.

Although some emotion-based reactions contained religious themes, this subcategory is temporally and qualitatively distinct from the subcategory of *religion*. The latter

category reflects a more long-term coping mechanism that is utilized throughout the

cancer experience. Interestingly, the women who perceived themselves as more spiritual

or agnostic than overtly religious typically exhibited task-oriented reactions rather than

emotion-based reactions.

Task-oriented reaction. As a way to simultaneously manage the shock of receiving a cancer diagnosis and make appropriate decisions to increase their chances of

survival, half of the participants engaged in specific task-oriented activities. Some of these participants described the importance of creating living wills to alleviate the burden of paperwork for family and to ensure that their possessions would be properly distributed to particular family members. Faith even wrote her own eulogy in order to make certain that her feelings for her family would be expressed accurately at her funeral.

She noted:

I did a lot of writing, a lot of gettin' the papers out and cleanin' up the papers and gettin' the insurance papers together. You get ready, in other words. You get ready for your funeral. I wrote my obituary, I put the insurance papers together, I wrote notes to the children.

For many of the participants who approached their diagnosis in a task-oriented way, this gave them the opportunity to focus their attention on immediate and necessary steps to successfully progress through treatment. Task-oriented reactions also allowed them pockets of moments free from thinking about the possibility of their death. Susie described her method of distraction:

Well, like I say, I try not to think about the cancer. I think about how long this going to take to run in, the chemo, and what time I'm gonna get through and what I'm gonna do when I get home.

Lily's method of refocusing her attention on more immediate tasks was similar to the method used by Susie:

My daily worries seemed to be focused on the immediate things. I think that's pretty much what carried me through, just focusing on things I had to focus on. I actually I had a long-term list and short-term list of things I had to do and I mostly approached it in a task-oriented way...to make it through.

For participants who engaged in a more of a task-oriented approach, the value in being organized, gathering pertinent information, and actively participating in the

treatment process was clearly evident in the benefits they received as a result. Being able to organize treatment options allowed participants to gain knowledge of all viable options for an optimal outcome. Lily was even willing to endure much physical pain at the onset of treatment if it meant treating the cancer as aggressively as possible to quickly eradicate it. She reported, “I just said I would like to have things treated as aggressively as possible because that scares me and I wanted more control over things. I wanted things to be dealt with and eradicated.”

These women also spoke about the importance of feeling in control over survival and the comfort in being able to approach cancer in familiar ways as they would with any other life challenge. Rebecca described a sense of satisfaction she felt in approaching cancer in a task-oriented way and being able to check off on a list. For her, this was the most comfortable way of managing her diagnosis.

Emotion-based reaction. Because of the nature of receiving a potentially life threatening diagnosis such as cancer, for some women as a survival mechanism, this meant focusing on specific feelings or emotions and relying on internal emotional strength to manage receiving the news of cancer. Jean talked about how she emotionally dealt with her disease:

And right away, [the doctor] said...told me that I had cancer. Well, I never worried about it. I didn't worry about it. I didn't get upset or nothin'. I dealt with it real good and I'm still dealin' with it. I try to be strong.

Another component of this subcategory was the process of gaining confidence in one's survival by witnessing seemingly miraculous recoveries of friends or family members who had been diagnosed with cancer. Using others as a gauge for survival

allowed some participants to reassure themselves that sometimes death could be defied, that doctors could be wrong, and that even for those who were on the brink of death could sometimes escape unscathed. One participant reported having two relatives with cancer who were predicted by doctors to die relatively soon but did not as a result of divine intervention. The experience of watching her uncle and cousin survive cancer despite their doctors' predictions for low survival was deeply meaningful for Jean, as illustrated by the following statement:

I don't care how sick you are, how bad off, you got somebody that sits up high and He knows. [...] The doctors can help us but we gotta a god that helps us too because I went through—I looked at my uncle and they said—they called everybody to the hospital and said he was gonna die. He didn't die, he lived for years and years. Same thing with my cousin. He had bone cancer but he lived a long time. [...] A lot of people may not believe—man doesn't do it, God does it. Doctors help us but we gotta somebody else that helps us too, more than the doctors. 'Cause we ain't gonna die till the Lord get ready for us so I never was afraid and I'm not afraid of dyin'.

Most participants who described having an emotion-based reaction to their diagnosis cited the importance of having an intuitive feeling that helped them assess their rate of survival. Lula spoke about her own mother's experience with the process of dying and how her mother knew at the gut level that she was going to die soon. Therefore, for Lula, the hope that she felt for surviving cancer hinged on the absence of a similar gut level feeling that she was going to die.

Managing Awareness of One's Own Mortality.

This category reflects the function of certain socially-sanctioned behaviors in managing participants' awareness of their own mortality as a result of their cancer diagnosis. Engaging in these behaviors not only gave these women a sense of dignity and

identity that allowed them to fight symbolically and/or literally against death, but also permitted them to derive a sense of meaning and purpose in life. Further, taking an active role in specific activities and interactions helped participants to manage the disruptions of cancer on a physical and psychological level as well as minimize cancer-related stress.

The data contained in this category were divided into six subcategories. The first subcategory, *relationships*, contained elements that illustrated the function of family, friends, and spouses as part of the cancer experience. The second subcategory was labeled *religion*, which reflects the use of religious beliefs as a way to find meaning in cancer and security from imminent death. This subcategory includes the concept of immortality (e.g., soul never dies) and heaven, a predetermined time on earth, the power of God, and cancer as a “lesson” from God (e.g., highlight a blind spot). The third subcategory, *belief in a higher power*, reflects the experiences of participants who believed that events and occurrences were aligned for a reason (e.g., meeting their physician, being accepted into certain clinical trials) by a higher power without an overtly religious tone. *Leaving a legacy*, the fourth subcategory, illustrates ways of establishing one’s personal mark on the world through passing on a family legacy (e.g., being remembered in a certain way), participating in community outreach, and giving back to the scientific community. The fifth subcategory, *independence*, encompasses the importance of establishing a sense of freedom and independence as a way to maintain one’s identity through productivity. This was exemplified by certain behaviors (e.g., being able to live alone, running errands) and feelings (e.g., sense of self-efficacy). The sixth and final subcategory was labeled *importance of roles*, which illustrates the

necessity of maintaining and engaging in certain traditional family, social, and community roles as ways to maintain one's identity and derive meaning from life. Examples include attending church, providing for the family, and participating in uniquely personal activities such as a hobby.

Relationships. The quality and stability of interpersonal relationships varied along a continuum. Regardless of whether participants experienced a growth or a fracture in their interpersonal interactions with family and friends, relationships with loved ones were acknowledged as an important factor in the healing process for these women.

Several of the participants indicated that they experienced no change in how close they felt to their loved ones and that this consistency helped to establish a sense of normalcy in their lives. This was instrumental in allowing them to feel like the same person rather than someone with cancer. Susan recalled how much she appreciated being treated in a familiar way, "Oh, it makes you feel good [that] people, you know, look at you the same as whether you had it or you didn't have it. It makes you feel good about it. ...they're the same before you had cancer as it is with cancer." Molly reported having a similar experience. She stated:

My relationship with my children and granddaughter has always been good and nothing's changed really about that. I have talked to them about the cancer thing when I first was diag—well, no, not when I was first diagnosed, I just told them I had cancer. But since I've learned more, I pass it onto them and it seems to have helped them understand more and all so it's helped all of us. But we're all dealin' with it now and in our own way, you know? ...I'm peaceful about it. Very peaceful.

Most of the women reported an increase in the quality of their relationships with loved ones and expressed feeling surprised, grateful, and touched by the outpouring of

support from their family, social groups, and community. The cocoon of maintaining relationships with important others and feeling supported gave these participants a sense of security that they were a valued member in their respective communities. One participant remarked, “It just makes you feel better when people comin’ around, talkin’ with you and things. ...it make you feel good that people care.” Susie described her experience in growing closer to her family, friends, and church community:

Well, I feel closer to ‘em because I know that they really care. Before I thought they were just friends, normal friends you’d have. Most of ‘em are really, really concerned and upset that I’m sick. And it makes you feel fairly good that people care. And all of ‘em put me on prayers chains and of course the preacher puts me on prayer chains at church. Everybody’s shown lots of concern, which I appreciate.

For some participants, friendships were the primary source of comfort in an often chaotic and unpredictable cancer experience. This was true for Lula, who brought her closest friend with her to every chemotherapy treatment. The presence of loved ones was particularly important during treatment and, if applicable, the rehabilitation process after surgery. Lula described the emotional benefits of having meaningful relationships:

Joy, peace, love. More than anything, understanding. Patience, time. I don’t have a large family, but what I have it’s kinda close. I have a brother and a sister. And my friends, that’s all I need. I need friends.

Participants with children and grandchildren reported wanting to spend more time with them. For some, physical limitations as a result of cancer treatment forced them to move closer to family or rearrange living situations; whereas for others, the decision to geographically relocate themselves near their children and grandchildren was intentional and unrelated to any physical problems. Lily expressed her happiness in being able to see her family more often, stating:

Oh, it's wonderful. I've been seeing my daughter every week at least and, sometimes, more than a couple times of week. It's been nice. And my son lives in Baltimore so he comes out more often with his son. So it's been nice.

Although most of the participants expressed a strengthening in their relationships, one participant, the “infrequent gem” in this subcategory, experienced the opposite.

Jennifer expressed that she had endured quite a different experience with her family. She described feeling angry and saddened that her loved ones did not respond to her suffering despite her having made herself available to them in their time of need. For Jennifer, forgiving her family for their actions and accepting them for their limitations was still a slow and ongoing process. She admitted that she felt partially responsible for the actions of her family for often having let them take advantage of her giving nature. She discussed the difficulties in letting go of the caretaker role now that she was sick. Jennifer worried that releasing herself from this familiar role would severely damage her relationship with certain family members, specifically her mother and mother-in-law, but acknowledged that refocusing attention to herself was crucial in the healing process of her mind and body. She said that she felt “so grateful because my husband never left my side and as you can see, he's still here today.”

Another atypical experience was described by Rebecca, who, despite having gratitude for the support of her family and friends, spoke about how her intensified relationships with her daughter and husband could become stifling:

Very protective, much more now...much more now. And monitors a lot, “Did you do this? Did you do that? Did you get this? How are you feeling? Did you eat today?” Those types of things. Much more protective so I worry about [my husband] sometimes worrying about me. My daughter is also a worrier, she always every treatment, “Tell me what the doctor said.” I have to call her and tell her what's goin' on—a year now! Every three weeks for a year, “How's things

goin’? What the test say? What did she say? Did you ask her this? Mom, I’ve been reading this, did you do—” You know, so they’re very supportive but have a tendency to be a little worry wart ‘cause I’m fine.

Religion. Religion was the primary method for managing death anxiety for most of the participants. Although three participants during the interviews indicated that they did not hold strong religious beliefs, particularly on the concept of immortality, or that they primarily relied on spirituality and mindfulness, all of the participants reported on the demographic questionnaire given to them prior to the interviews that they were affiliated with a specific religious denomination. These religious denominations were all based on Christian-centered beliefs. As previously stated, this subcategory differs temporally and qualitatively from that of *emotion-based reaction*. This *religion* subcategory focuses solely on the use of religious beliefs and practices as a long-term coping tool to manage having cancer whereas *emotion-based reaction* reflects the focus on immediate internal arousal following a cancer diagnosis.

Of the women who strongly adhered to religious tenets, several of them reported believing in the immortal nature of the soul and that, as a result, at least for those who are saved, one will never die. Those holding strong religious beliefs spoke about the comfort they felt of having the protection of an omnipotent god. Several participants described in detail the peace and comfort they received from feeling protected by God:

Molly (*Protestant*): I think if you believe in God and do the best of your abilities to follow His teachings, that you will be taken into heaven and you will live forever with Him, so that’s my whole thing of peace right there. ...I don’t believe that my soul dies, I believe my soul will go to heaven and I will continue on in heaven and that’s just part of the living process...to me.

Jean (Baptist): If I had this cancer and it caused me to die when God get ready for me, I'm gonna die. But I don't dwell on that, I don't dwell on dyin', I don't think about it.

Susan (Baptist): But even with cancer, you know, you got it and you pray to the Lord and ask for His strength and go on from there. Just believe.

Lula (Methodist): I want to be a survivor, I pray hard everyday that God will take care of me which I think he will—I know He will. So, no doubt in my mind He will.

For Jennifer, there was no question that God would save her from dying of cancer. She stated, "My first thought of when I was told was... 'Okay, the Lord has to heal me.' That was my first thought." She further described how she knew death would not be the end result of cancer by directly speaking to God through prayer:

For me to be honest, I wasn't concerned about dying. It sounds very silly but, no, that wasn't an initial thought. I won't sit here and say that the thought has never crossed my mind. Of course it has, especially when I started treatment and...[it] got very difficult...just bein' sick and weak, but my faith endured throughout that. And once I got word from the Lord and that's really what happened for me. I read the word, I prayed, I asked for an answer, He gave it to me, and I knew that I was gonna be all right. And on top of that, even if I did, my belief would just tell me I'm gonna be fine.

For others, like Lula, there were additional components to her faith such as the idea of one day being united with God and reunited with their loved ones after death as well as being free from sickness. She explained:

It's a lot of things about leaving people here, loved ones, family, friends, but being reunited with family and friends that have gone on before...that there won't be any aches or pain or cancer, no sickness. Everybody will be well, which I think would be wonderful.

Molly expressed similar beliefs:

...I know I have loved ones that have gone on before me and I firmly believe that I will meet them in heaven. And the people I'll leave behind, I'm sure I will meet them in heaven. And if everybody would understand that the way that I'm

understanding it, they would be a whole lot more relieved and, that is, fearful of the death aspect of it. But I firmly believe in heaven, God in heaven, and I'm just not afraid. So that's mainly all there is on that, I just...read my Bible everyday and it brings me a lot of peace.

Susan spoke about simply relishing in the joy of being with God after death. She expressed her desire of “hop[ing] I be with the Lord, Jesus Christ. Singin' up there, I can't do much of a singin' but I guess I would. I guess I would start a tune.” Another desirable piece of relying on religious beliefs to manage cancer and the subsequent awareness of one's own mortality is the reassurance that God will intervene when the limitations of human ability and medicine are reached. Jennifer spoke about this concept:

But there are points where the doctors can't do anything else anymore and that's where, for me, God comes in. If somebody tells me something is possible, I know that the word of God tells me what's impossible to man is possible for God.

Participants also discussed finding a reason or a purpose of having cancer that God intended for them to uncover through the process. For Jean, not clearly understanding God's purpose for having cancer was acceptable to her as evidenced by the following statement:

He gonna have somethin' for you somebody but you don't know what it is. He got somethin' in store for all of us and we don't know what it's gonna be. We don't know how we gonna be in this life. We don't know what's gonna happen to us in this life. We don't know. These things we don't know.

Conversely, Jennifer believed that she had a clear understanding of the reason why she had cancer after praying to God. She said, “...those reasons unfolded to me. Part of it was because I had a blind spot that He needed to uncover. I wasn't seein' basically—I couldn't even live out my own life because I was totally consumed by others...” She further described taking the necessary steps in disentangling herself from

select members of her family in order to focus on self care. Jennifer stated that having a cancer diagnosis highlighted a “blind spot” for her, meaning that because of cancer, she finally was able to recognize that her giving nature had been taken advantage of by her family members. Despite the severity of a cancer diagnosis, Jennifer expressed that she was grateful to God for giving her the opportunity to come to this new realization.

Belief in a higher power. The two participants who indicated that they were either more spiritual or did not adhere to specific religious beliefs spoke about feeling the presence of a higher power that was carefully aligning events in order to help them manage and get through cancer. Rebecca described her experience of being introduced to her current physician for treatment, stating, “...once I found Dr. [X], I felt like this was the path that I was meant to go on. You know, she was put there for a reason.” She added that, “...all of a sudden I’m looking at clinical trials rather than just regular treatment. So the doors have opened up. Just out of the blue, the door opened up. I got in and there were two or three slots left... There’s a reason for that.” When asked how she made sense of this, she answered, “...this is my plan. I’m living the plan.”

Lily spoke about her own experience with her husband who suffered from a brain aneurysm several years ago. She recalled the number of times his doctors told her he was on the brink of death and how he managed to survive each time. As a result of these experiences, she believed that there was a specific amount of time designated for each person on earth although she did not know who or what designated this time or when death would occur. For her, knowing this gave her comfort that because her fate was

already pre-determined, cancer would not necessarily be the event that would take her life.

Lucille, who denied having a strong religious affiliation or belief in a higher power, described her skepticism of religion and the way that she managed death anxiety without relying on religion or spirituality:

When you pass away you don't know what happens and you hope that it's not a terrible thing to do and you hope it's all as good as they tell you it's gonna be, but I don't think it's anything you—to me, it's not anything you can really know. ...I guess I just hope that it won't be...a bad thing and that's about all I can think about it. People have very different reactions to it, especially if they are especially what they call religious. You know what I mean, read Bibles and read their whatever...and I think that's wonderful because I guess it gives you a deeper feeling of, "I know it's gonna happen" but then when I'm thinkin' about it, I think, "Well, no they don't...they don't know any more than I do or anybody else does because nobody's ever come back to tell us what it's really about." ...It probably gives them a much warmer better feeling about it maybe about death to that particular person, but I don't know if that helps somebody or doesn't. I really don't.

Leaving a legacy. When the interviewer asked the question, "What is living for you?" the responses of the participants varied greatly; however, the common theme was that the essence of living involved finding one's purpose and meaning in life. In addition, through the iterative data analysis process, these units of data illustrated the concept of leaving a mark on the world after death or sharing information in a way that could be passed on through generations, which embodied the definition of legacy. Examples of this process are passing on values to loved ones and contributing to society at large by helping community members in need.

For participants who had children, being a mother was largely thought of as one's life purpose and that satisfaction of raising their children brought meaning into their lives.

Molly, a mother of three, explained the importance of leaving a legacy for her children and grandchildren by being an inspirational role model:

Your children are always your children. It doesn't matter if they're 80 years old, you know? But they give me a lot of encouragement and strength and hopefully—and I think I do—give them the same thing because I feel like if I'm strong during this cancer, if I'm strong for myself and I'm also strong for them and showing them that you can always come up from anything. You can always come up; it doesn't have to be just gettin' you completely down. You can always come up, there's always a way. It may take some time but it will happen and so hopefully by my doing that, then they can see that it's—and that's basically, my life has been for my children really. And grandchildren.

Community outreach and personal projects were also considered important by the majority of the participants in managing cancer and finding personal meaning. Several participants were volunteers within their local community centers or churches. Faith discussed her volunteer work in a nursing home and the satisfaction she receives from this type of work:

I have a project. ...At the night the thought comes in, somebody's name. Sometimes I send things to people in the nursing home. It's just like...missionary work and it's a job. I said, 'Well, [God] took away that job but now I have another job.' And I be listening.

For participants like Lula and Jennifer, using their own cancer experience as tools to help others manage their disease allowed them to feel as if they were fulfilling a purpose. They described:

Lula: It would give me a feeling of helping, using my sickness to encourage somebody else just like I've had several people talk to me that have had cancer that helped me. ...That that's gonna be—that's my goal, to do good and to be able to talk about it and I feel good now. People ask me how I feel, I feel good.

Jennifer: I still feel like if I'm here, I want to give somebody else some hope. Because everybody doesn't have the hope that I have, everybody's not—of course, people have been in here too many times and I have spoken to women in

tears that they do feel like it's a death sentence. It's not—even in a medical world [cancer is] not necessarily a death sentence.

For Lily, there was a hierarchy in establishing a legacy for herself. Taking on personal projects to benefit her family took precedence over participating in community volunteer work, although both were contributions that she deeply valued. She expressed:

I want to be able to sew and finish the projects I was doing, finish the quilts, organize my photographs. [...] Get those organized and dated and put in order. I want to do that, I want to get my stamp collection that I've had since I was kid ready to sell. Just little projects. I want to get these projects done and some of them I'll continue on like the quilts, I want to sew some quilts for the grandkids. I have some that are in the process that I'd like to finish and I'm not sure what else. I'd like to maybe do some volunteer work if we can...and help out maybe in some rehabilitation center with my husband, maybe play bingo, teach, run a bingo thing or just to sit with people and do something like that. It helped him a lot when he was in rehabilitation and I just want to help other people.

Three participants discussed the importance of giving back to the scientific community either through donating one's body to science or participating in clinical trials. Susie and Molly reported that they were planning on donating their bodies to science and how meaningful this would be to both of them. Susie aptly summarized her rationale:

Well, I decided that I was going to donate my body to science after [death]. They take everything they can take to use to help somebody. I mean, if they can take my eyes or my skin or bone or cells or blood or whatever and help somebody else, that's what I want done and then after they've used everything that they've used, then research and science and so forth, then cremate the rest of it. Because I can't see burying something that somebody could use.

Rebecca expressed her belief that those who were eligible should participate in clinical trials to benefit other patients for new treatment options:

...the whole point of a clinical trial is not only helping yourself but giving some kind of history so that this drug can be available for a lot people. 'Cause I tell

everybody I know, I say, “If you ever have chance to get in a study... You know, you need to do it because it’s really doing some good things, some good things.”

Independence. For women who experienced major physical limitations and side effects as a result of surgery and/or chemotherapy, the common theme found within this subcategory was loss of identity through loss of productivity. A number of participants struggled with being heavily dependent on others to perform basic activities such as showering, performing chores, and cooking. Participants with children, who had strong identities as mothers, reported feeling frustrated at the role reversals they experienced with their children and having to relying on them for the simplest activities. All of the women identified with the difficulties of transitioning from being a highly productive member of society to having to limit their typical work load or involvement in certain activities.

Given that reclaiming independence was a huge marker of success, particularly because all of the participants reported having led active lifestyles prior to cancer, some exhibited great determination to increase their physical mobility when improvement was slow to occur. Jean’s description of her willpower to increase her mobility is a prime example of her fiercely independent nature:

At least I can get up and take care of myself. Don’t nobody have to bathe me, comb my hair. I make my bed, I cook my food ‘cause if I didn’t have to strength to do it I wouldn’t be able to do that. That first week I tried to make my bed, it must’ve took me thirty minutes to make that bed ‘cause I was weak but I tried. And when I wanted to cook, they wouldn’t let me cook, I said, “I can cook an egg, I can make a pot of coffee, I can make a piece of toast. I don’t need nobody up here doin’ this for me. Let me do this.” And that gets me up, motorized and get to do doin’ somethin’ and that’s how I get strong, get strong doin’ somethin’. You can’t get strong layin’ in the bed, you gotta get up. And I’m not a person that lays in the bed. I love to get up and do things.

Susie recalled watching her own grandmother assert her independence until she became very ill and how she wanted to model herself after the strength her grandmother displayed prior to her death:

I've always done everything myself and I know you can't predict what's gonna happen. But I kinda take after my grandmother. My grandmother was the same way. She was very, very active. Of course, she died of cancer too. But up until she died, until she got sick, she was extremely active and did everything for herself and I'm the same way and would like to continue that way. Of course, I know I'm 77 so I don't have too many more years of bein' real active, but I hope I'll have as many as I can.

For participants like Lucille, unlike Jean, sheer willpower alone was not enough to force her body to move in the way that it once did. She described the feeling of utter helplessness when she was physically unable to do things on her own: "...just this complete...dependency. Yeah, feeling of uselessness to yourself. Not so much to other people, but to yourself that you can't...just can't do anything." She further elaborated on an incident where she collapsed at her daughter's house and had to be physically lifted by her daughter and son-in-law. This description illustrated her experience of being completely dependent and feeling useless to regaining some of her strength to function more independently:

I can't dress myself...it's an absolute awful feeling. One day, Beth [my daughter] wasn't at home...and I don't remember what happened but I slipped down to my knees and then I couldn't get up off the floor. I could not get up off the floor. I had to call [my son-in-law] to come down and lift me up... those kinds of things where you can't take a shower by yourself, you know what I mean? You think this is really...mmm...really awful. And...even though they're doin' it with no—to them they're not given any bad feelings or, you know what I mean, they don't mind doin' it and all this kind of stuff, you feel like a complete like a baby, like a complete burden, you can't do anything. [...] Now it's gone to the other extent in the fact that I can do practically—within reason—I can do practically anything for myself again, which makes me feel very, very much better.

Participants also spoke about how being taken care of was a foreign experience for them and that having to accept physical help from others dampened their spirits. For most, learning how to ask and accept help from others was a difficult process. Jennifer, the only participant who had not received social support from her family, discussed the difficulty in simply being sick after encompassing the role of the healthy caretaker for so long:

...it was such a shift for me because I never really had to wait on or accept somebody to help me. I had never had that—go through that where I never had that desire to have somebody to be around me or comfort me because I had never really been sick. I had never had any major illnesses like I said. For the most part, I was the one who would help everybody else out.

The challenge for participants like Faith was having the outpouring of support from loved ones and learning how to accept help. She described one story:

...the pastor would call and she said, “What you do today?” I said, “I can’t do nothin’. My head will just not get off of this pillow.” “Well don’t do nothin’ then!” You know, it’s like it’s all right not do nothin’. To me it’s not all right not do nothin’. That kills me!

During her interview, she became particularly emotional when discussing the indignation, anger, and frustration she felt at her physical limitations and having to receive assistance even when she needed it the most:

...it was hard to accept help and they said, “We came to help you” and I said, “I’m a do it in a minute.” ‘Cause I was always so independent and they would get angry and I said, well—for a long time—well, I’ll save somethin’ for them to do. Because I wasn’t doin’ it. I couldn’t do it! But my mind said I was gonna do it after awhile and that was probably a year and half realizin’ that. Couldn’t do a simple thing. Get the mail, fall on the floor. Can’t get it. I could go to the kitchen when they got me up and I started walkin’. Get somethin’ to drink, couldn’t cook. Always cooked all the time so learnin’ the limitations, that’s hard.

Importance of roles. For all individuals, regardless of a cancer diagnosis, engaging in certain social roles allows us to structure our lives and find meaning and purpose. Maintaining these roles, such as “mother,” “wife” or “church member,” became even more necessary and meaningful for the participants after their cancer diagnosis. Because cancer, by its nature, is destructive and disruptive, these roles provided a way for these women to regain structure, familiarity, identification, and positive feedback.

Jennifer’s description fit the core of this subcategory:

We all have a purpose and sometimes you don’t even know. Some people don’t know, “Okay, what in the world am I here for?” It’s not just to wake up every day and die one day. There’s something that only each person can do. Every person is unique and only they can only do certain things.

She further elaborated on the important roles that she believes she was called to fulfill by God:

One of the things that I’m called to do is to assist my husband and what God called him to do and so He just let me be doin’ what I’m supposed to be: his administrator for the business. My husband is the one who does it so I just need to back him up, that’s one thing. But as far as why I’m here, I’m destined to become more like Jesus was. Now I gotta long way to go, I’m not gonna lie to you. [Laughs] That’s my destiny. That’s what He really want me to be is to be more like Him. ...But then there’s the other thing. One of my callings is to exert and to encourage people and that’s what I’m called to do. Because there’s so many people in despair everyday, just to encourage them that they can make it, that they can do it. Because some people give up and if only they had one person constantly to believe in them or to make a comment to them saying, “You know what? That idea you have is great. Don’t sit on that. Go ahead and do it. Make it a reality.” That’s what I’m called to do is to encourage others.

For participants like Molly and Faith, the role of being a mother and the emotional reward of caring for their children, regardless of the children’s ages, imbued their lives with meaning and happiness. They each spoke about their own experiences as mothers:

Molly (mother of 3): You know, “Why was I put—what am I supposed to do?” And to me it always goes back to my children. I’ve raised them, now they can come to me for advice, I can receive their help if I need anything and it’s just...I don’t really know how to put it, it’s just life, it’s just my life. That’s the way I feel. [...] Yeah, when I think about my children, I don’t know how put it into words. I thank God for them everyday. They’ve given me a meaning in my life, not just since cancer, before cancer, a purpose and I love them. Whenever I think—I have three children—whenever I think about any one of the three, it’s always a happy feeling, a joyous feeling so it’s about it with them. That’s the way it’s been, that’s the way it still is, and I know the way it’ll always be.

Faith (mother of 2): And the motherly instinct, if you had children, the mother instinct kicks in because you still have that, “I’m takin’ care of ‘em” or “Christmas is comin’ and I gotta get ‘em somethin’” or “Thanksgiving’s comin’, I gotta cook somethin’.” The tradition and stuff that’s imbedded in you just stays there and it doesn’t matter how old your children are. You always gettin’ ready for somethin’. If they’re away, they’re comin’ up, I’m a cook.

In general, participants found it necessary to maintain specific roles after diagnosis as a way to find meaning and purpose in life, and for most participants these were typical, everyday roles.

Dignity Overrides Self-preservation

This category focuses on the personal line drawn between fighting for survival and accepting death as a reality. Death as a way to avoid prolonged incapacitation, helplessness or suffering, states of being that would strip individuals of their dignity and inflict pain on their loved ones, typically overrode self-preservation. For majority of the women, the limit was clear as to where they would draw the line between self-preservation and death. Because of the uncertainty of surviving any serious illness and the sense of meaning and identity derived from certain socially-sanctioned behaviors that buffers this uncertainty, the inability to fully engage in life would leave an unacceptable void for some of the participants. At the core, these participants wanted preserve their

sense of dignity and they did this in various ways such as engaging in productive activities, running errands, playing with their grandchildren, visiting friends, and attending church—the enjoyable aspects of life that helped define who they are.

Susie, who has an extensive personal and family history of cancer, discussed how experiencing the deaths of her loved ones affected her:

My view on life changed back in, like, 1979 when all of my daddy, my sister, my mother, and then my husband, goin' through all that, particularly with my husband. Yeah, it changed a lot. ...if it wasn't for me, he would've been in a nursing home and that's terrible. I don't ever want to go through a nursing home. Ever. I'd rather die than go to a nursing home.

She further described witnessing the painful dying process of her sister and father: "...I'd rather commit suicide than to go through what they went through, which I would. I probably won't but it did make me think about that, that I was not gonna go through that." Lula expressed a similar view, stating, "I don't want to suffer. I would rather go than suffer as I would rather see my loved ones go rather than suffer."

Some participants worried about inflicting pain on their families or being a burden should they become physically unable to take care of themselves. Lucille described her fear of being an inconvenience to her daughter and son-in-law: "I don't want Bob and Beth and so forth to be havin' me as this big problem. What are we gonna do with momma?" One participant, Jean, even had specific instructions in place in order to avoid the possibility of her children having to care for her: "I don't want to suffer. When the time comes for me to go, I just want to go. I don't wanna lay here and suffer and be no worry to my kids and this and that...they have to put me in a nursing home."

For Lily, her concern was more directed toward the possibility of being incapacitated over suffering or being a burden as evidenced by the following statement:

...I don't want to be to the point where I'm incapacitated and can't do things, function in life. To me I want to be able to do things, go shopping, and do things with grandkids and, you know, be able to be active ...I wanna go to the beach, I want to have picnics, go to King's Dominion, be with the grandkids, do things that make them happy and we all can enjoy. ...I wouldn't wanna be disabled. I think that's the biggest thing or really, really sick. To me that's worse. ...I would just hate to be inactive and not be able to do anything. It would just be a horrible way to live, wouldn't it?

The participants in general wanted to avoid putting additional stress on the family as a result of being incapacitated due to physical limitations or intense pain. The underlying message behind the participants' stories was that although they wanted to survive cancer, they were not willing to do so at the expense of their family's happiness, which, as previously noted, was a large component in finding meaning in one's life.

Integration of Cancer into Life

This category reflects the outcome of managing a cancer diagnosis through the mechanisms described above. The women who participated in the present study were not facing imminent death due to their cancer diagnosis and, based on the interviews, worked to integrate cancer into their daily lives by being able to identify certain advantages or benefits from having cancer. This process greatly differed among the participants and, interestingly, at least for religious participants, had little to do with their beliefs about God. For participants like Faith, being able to gain a unique perspective as a result of having cancer and to develop empathy for other patients allowed her to develop a passion for helping others in the face of cancer:

...when you see other people you know how they feel, you know, when they get old and have a walker and a cane. You never walked on one of those, you can't imagine. You never been in a wheelchair, you can't imagine. So that's basically like I said, busyin' yourself and it's just a passion and it's a personal thing. Like I said, you can sit and you can wait or you can get up and do. It's up to you.

A different, more personal experience occurred for Jennifer after being diagnosed with cancer. She reported having to learn how to take time for herself, which she felt without cancer, she would not have been able to do otherwise. She described cancer as a learning experience:

And to that I'm thankful to cancer for 'cause if I hadn't gotten sick, I don't think I would've ever realized it. I think I would've gone on to the point where maybe I wouldn't have been able to turn my life around. I might have been too old at that time, not havin' enough energy or resources to do something about it but this made me face my life and say, "What in the world?" You can love people and you can do for people and there's nothing certainly nothing wrong with that and I still will, but I have to know when to say no. I have to know when to stop and also know when to take care yourself. I wanted to kind of stop and say, "I don't have enough energy to share right now. I would like to but I don't have enough to share."

Susie was able to integrate cancer into her life by enjoying her current state of health, feeling active, and consciously denying death:

Well, it makes me feel better, you know? To think that I might be able to live a couple of years more. And as long as I can be as well as I am now. If I were bed ridden or things would change, but I feel pretty good and I can do right many things so I feel pretty good about everything. I don't think my time has come yet, I'll put it that way. I'm pushin' it off. I say, "You stay on that side of the door."

She summed up her view as "...life is not too bad even though I've got cancer. Like I say, as long as I think of other things, I'm fine." Similar to Susie, Susan described consciously avoiding ruminating about cancer and living in the moment. She expressed her opinion:

The best thing to do is go on and live day by day. That's the best thing you can do. If you just sit and worry about, "I have cancer," that gonna pull you down more. You are goin' downhill, but if you go on, try to make your life as best as you can, that's the best way to go.

For Rebecca, not unlike Susan, the focus was on living in the moment. She said she focused on, "Enjoying what I have and making the most of where I am right now. It's a good thing, good thing." Her description of cancer as a "growth experience" was similar to Jennifer's view that cancer had been a "learning experience." Rebecca further elaborated on her own personal philosophy and the positive influences cancer has had on her life:

I didn't take things for granted. I appreciated little things, I'm living in the present. Not living in the past, not living in the future, I'm just living for life which is a great thing to do. ...because everybody's racing forward and we're thinking about all what's happened in the past, but I look forward to what today's gonna bring, what's goin' on right now. And I'm kind of a high energy gal so it's just kinda step back and take a deep breath and say, "Okay, just be here. Be in the now." I appreciate what's goin' in the now, just make the most of what we have right now.

For Rebecca, she believed that she never would have reached this state of appreciating the present if she had not had cancer. She remarked, "I don't think you really do it until you have something life changing happen to you."

Molly reported simply being grateful for her life. This sense of gratitude allowed her to say, "Yes, I have cancer and I've had surgery but I'm still alive and I can see myself getting a little better each day." She further elaborated:

I feel like I'm a very lucky person. Even if I do have Stage III ovarian cancer. I don't look at that as...anything bad, it's just something that happened to me and I take it in stride so to speak. I feel like I'm a very lucky person.

Lucille, the oldest participant at age 80, spoke about accepting the fact that death might be a possibility, whether due to old age or cancer and that this was part of accepting cancer into her life. She expressed her thoughts about accepting death as a possibility and how she would feel if her doctors told her that treatment would no longer benefit her:

I would have to accept the fact from [the doctors] that, okay, we're not able to keep going forward to help you. We've come to a standstill or maybe you're going—or maybe I'm going backwards, but there's nothing that can be done about that. I mean, they're doing the best they can do at this point I feel, so if they start telling me there's no more to do for me then I'd have to accept whatever they thought was the best solution. I'd have to listen to it, I wouldn't have to do it... I don't see how you could do anything else, but when they look at you and say they'd done all they can. There's no need to feel like you gonna fight it or somethin'. I don't think you can. You take—you do whatever they say to help yourself but you can't really change the course of what's gonna happen.

For the older participants, the idea of accepting death as a near possibility was not a foreign concept simply because of their age. Lucille spoke about her sister's attitude toward dying of cancer and, in response to her own diagnosis, stated, "You know something is going to take me away... And maybe it's going to be this." Others discussed the process of releasing control, letting life take its course, and acknowledging that if cancer were the end for them, that they at the very least would not be dying young. Faith brought up the unpredictability of life and how one could not avoid chance occurrences in life that could result in death. She described in a frank manner:

Somethin' could happen...an accident, anything. So we just have to take it as it comes. That's the way that I look at it 'cause we don't know what day it is even with the ones who don't have cancer. You don't know if you gonna live tomorrow.

CHAPTER FIVE

Discussion

The primary goal of this study was to gather rich information on the ways in which women with gynecologic cancer managed the anxiety that arose from the sudden awareness of their mortality created by the diagnosis. This study was based on an interpretive approach that allowed for the emergence of themes and nuanced information through individual interviews. The previous chapter illuminated the ways participants managed their illness and sought to integrate cancer into their lives. This chapter will provide a summary of the findings and a discussion of how these findings fit with those from prior studies. In keeping with the interpretive grounded theory paradigm, this chapter also includes my personal experiences and reflections during the research process. I will also discuss the implications of my findings for theory, research, and practice.

Reflections during the Study

The grounded theory paradigm imposes limits on researcher subjectivity to minimize threats to trustworthiness. Accordingly, I kept a detailed reflexive journal to record my thoughts, feelings and potential biases to make conscious the ways in which my subjectivity could influence the research process. The following section details my personal experiences in conducting this study. My goal in sharing these thoughts is to

make transparent how and why the study came to fruition as it did based on my worldview, values, and experiences.

Prior experiences with cancer. Naturally, as with most research interests, I became interested in cancer research from personal experiences. My own mother was diagnosed with breast cancer when I was 13. I can recall the effort it took for my parents to rearrange their work schedules, the financial burden of treatment and recovery, the constant scheduling of treatment appointments, and watching my mother trying to minimize the physical toll of cancer to alleviate our worries. She survived the ordeal. That was the beginning of my interest in the area of oncology, particularly on psychosocial factors related to cancer. Several other cancer-related events followed, including the death of my graduate school advisor, Dr. Elizabeth Fries, in 2005 due to complications from breast cancer and my grandmother's recent breast cancer diagnosis.

In college, after choosing to undergo comprehensive health psychology research training, I knew that I wanted to focus my graduate studies on psycho-oncology research, specifically on gynecologic cancer. Some people have asked why I chose to study such a specific population. I do not have an eloquent answer, other than that I think, as a woman myself, that understanding the psychological issues that result from diseases of the female reproductive system are inherently interesting and important.

The dissertation. By the third year of graduate school, students should, at minimum, be formulating ideas for the dissertation. I knew I wanted to study women with gynecologic cancer. And I had seriously begun to consider using a qualitative research methodology for my dissertation. But I was missing something essential: the

topic. I read a variety of cancer research articles and textbooks, waiting for the moment where a topic would catch my interest. Nothing did and I began to feel frustrated.

Unrelated to the “Great Dissertation Topic Search,” I began reading Ernest Becker’s *The Denial of Death* for an independent reading study with Dr. Tim Hulse. Becker’s notion of man as half symbolic and half animal and the psychological complications that arise from this crucial dilemma was fascinating. His descriptions of the ways in which people attempt to resolve this uniquely human predicament was shocking, slightly disturbing, and initially quite depressing. But it was also compelling and intuitive and synthesized data from a range of disciplines quite nicely. I had found my missing link.

I was then introduced to Terror Management Theory, a relatively new area of research within experimental existential psychology. The more I read about these studies, the more I became interested in examining the concept of death anxiety in non-terminal gynecologic cancer patients. The gender-specific nature of gynecologic cancer also further captured my interest.

With the aims of the study identified, I could now turn my attention to the best way of capturing useful data on how these women managed the anxiety aroused by their diagnoses. Qualitative methodology fit well with my goal of gathering information from a relatively understudied cancer population through the use of individual interviews and permitted me to use my clinical interviewing skills. Dr. Kathy Ingram, my advisor, sensing my excitement, encouraged me to take complete creative control over the research process. Of course, with that came great responsibility. I vacillated between

moments of euphoria at carrying out a personally meaningful project to the sinking realization that I was primarily responsible for *everything*.

My goal was to understand the experience of dealing with a potentially life threatening diagnosis. I chose to use in the words of people who were forced to manage this existential crisis as the data. Cancer survivors are often depicted as perpetually optimistic individuals who maintain a cheerful fighting spirit as a way to defend against the effects of their disease. This is not a terrible portrayal but it is an inaccurate one. I wanted to understand the three-dimensional cancer experience: the good, the bad, and the in-between. And, I wanted to hear about it straight from the individuals themselves.

Interviews. I experienced a great deal of emotion during the interviews with my participants. In each woman, there was a characteristic or trait that I found admirable. I respected their frankness, spunk, fear and resilience. However, I struggled with two topics that came up often during the interviews. The first was religion. Because I have distanced myself from any religious beliefs or practices, I wrestled with quieting my own thoughts during interviews so I could be fully present when participants were sharing personal narratives on their beliefs. For me, relying on basic interviewing skills and being cognizant of grounded theory principles prevented me from becoming lost within my own head or reacting to participant stories negatively. But I still worried that I could not be objective about this. I consulted with my advisor during the coding process to make sure that I had not presented the data through the lens of a cantankerous nonbeliever.

The second issue involved my craving for something more from the interviews, possibly even something that resembled therapy. I suspected that this might happen. As a counseling psychology student, I believe that there is a certain level of depth we become accustomed to when conducting therapy. And, the setting in which participant interviews took place was not completely unlike that of a therapy situation. The participant and I were typically alone in the room, we faced each other, and the nature of the topic quickly forced us to bypass any small talk to delve into the meat of the matter. During some of the interviews, I found myself becoming slightly restless, wondering why I wasn't getting information that I felt would illustrate this messy, existential struggle that I assumed would occur after receiving a cancer diagnosis. The following is an excerpt from my reflexive journal, dated September 17, 2008:

At first, I wasn't sure if Lula would give an hour's worth of an interview. It was difficult at times to draw things out of her. I asked her to give me examples or tell me more about her thoughts and feelings on a particular subject, idea, or event. Lula gave fairly simple descriptive words such as "wonderful." She appeared to be comfortable talking about death and normalized these types of thoughts. I felt in therapy mode some of the time and made a lot of reflection comments though I tried not to put words in Lula's mouth. It was difficult not to go in therapy mode as a trained student.

I wrote continuously in my reflexive journal and discussed my struggles with fellow graduate students who were also conducting interviews for their qualitative projects. It was important for me to keep in mind that: 1) this was *not* therapy nor would it have been ethical to conduct interviews as if they were; and 2) the point of my research was to understand the unique, lived experiences of women with gynecologic cancer and not to confirm my own perspectives on the cancer experience.

Data interpretation. During the dissertation process I experienced certain life events that shaped the way I designed this study and how I interpreted the data. I read *The Denial of Death* when my personal life was in significant upheaval. I went from being moderately religious to distancing myself from all religious practices and beliefs. One of my classmates took her own life, forcing us all to face difficult questions about life, death, and meaning. I studied abroad in South Korea for two months in a cultural immersion program. My experiences there significantly changed the way I thought about the world and myself. I received clinical supervision from a psychologist who infused existential theory into his therapy and supervisory style. I started my practicum at an inpatient psychiatric hospital where many of my patients have committed heinous crimes. And I experienced a major increase in my own death anxiety as a result of the combination of these events. Just like my participants, I too began to grasp the fragility and unpredictability of life. I initially felt quite indignant because I thought being in my twenties granted me a cloak of invincibility and that death anxiety was something I should have been able to reserve for my mid- to late forties.

But this gradual increase in death anxiety proved to be advantageous. I was able to develop greater empathy for my participants as well as better understand the importance of certain religious practices even if my own beliefs differed fundamentally. And because awareness of one's own mortality is such a universal human experience (this is my belief, anyway), I was able to perceive myself as a genuine conversation partner when talking with participants. This allowed me to reduce the expectation that because I was the investigator, I was somehow the "expert." Although thinking about

death and the reality of our insignificance is not always pleasant, acknowledging and even embracing human frailty was important to this type of research. It also proved to be quite humbling and freeing.

The most humorous part of this entire experience was the reactions of others to my research. These reactions ranged from “Oh, really?!” to “Oh...really?” People with the latter response would size me up in my khakis and matching sweater set and I could almost hear them thinking, “Well, at least she doesn’t *look* morbid...” Regardless of the types of reactions I received, from individuals who were genuinely curious to those who were skeptical, talking with others allowed me to engage in stimulating conversations about my conceptual understanding of death anxiety and how relevant it was to the experience of cancer.

I have no illusions that the way in which I have interpreted and presented the data is the Truth. In fact, I expect others to disagree and argue for alternative ways the data could have been interpreted. I welcome these different perspectives. I simply hope that I have been able to contribute a deeper understanding of certain facets of the gynecologic cancer experience and a more comprehensive psychological picture of how patients manage this disease. I also hope that I have been able to give an honest depiction of the frustrating and gratifying components of this study, how this process has affected me on a professional and personal level, and why I interpreted the data in the way that I did.

Limitations

As with any research, there are several limitations of the current study. One is the scope of the study: to examine the lived experiences of women diagnosed with

gynecologic cancer. Thus, this study did not examine implications for policy or social action related to this phenomenon (Marshall & Rossman, 2006). However, study findings help illuminate participants' thoughts and feelings about mortality and may contribute to a more open dialogue between patients and their caregivers (e.g., family, physicians, and nurses). From a practical standpoint, clearer understanding of the psychological and existential experiences of women with gynecologic cancer could also help mental health professionals to tailor supportive psychotherapy offered in medical settings. Second, the use of interviewing as the only means of collecting data has several weaknesses (Marshall & Rossman). Interactive face-to-face interviewing may have been uncomfortable for some of the participants and thus, may have hindered their responses. Third, participants' experiences are not static; therefore, the information obtained from the participants can be considered an accurate view only for that moment in time.

Fourth, women who agreed to participate in the study were referred by two nurses in the cancer center, which may have led selection bias, a term used in quantitative research to describe the misrepresentation of data due to the way in which the data were collected. However, given the nature of purposeful sampling and the aim to recruit a more cohesive sample for data saturation purposes, perhaps the referrals based on the nurses who were familiar with their patients allowed for demographically similar women to be recruited. Fifth, because 70% of participants reported having Christian-based religious beliefs, it is unclear as to how individuals who identified themselves as non-Christian (e.g., Jewish, Muslim) or non-religious (e.g., agnostic, atheist) would have responded with regard to how they managed cancer and death anxiety. Last, there were

no participants with cervical cancer, a target subpopulation of this study. Although research has shown that, in general, there are no significant differences in quality of life or mood between the gynecologic cancer subpopulations, a study suggested that cervical cancer survivors reported more anxiety than their endometrial cancer counterparts (Bradley et al., 2006). Thus, it is possible that women with cervical cancer may have expressed greater despair with regards to managing awareness of their own mortality or may have provided qualitatively different data than women with endometrial/uterine cancer and ovarian cancer.

Summary

The purpose of this study was to develop a theoretical understanding of the following research question: “What are the experiences and processes by which women with gynecologic cancer construct meaning and manage death anxiety in the face of their diagnosis?” Ten women diagnosed with gynecologic cancer, a relatively understudied cancer population, were recruited and individually interviewed. Interpretive grounded theory analytic procedures (Charmaz, 2006) were used to uncover themes and categories imbedded in the data. After incorporating feedback from two auditors as well as the participants themselves, a total of 13 categories and subcategories were identified.

For all of the participants, cancer reminded them of their own human frailty that no one was immune to death, a notion that typically remained unconscious and out-of-awareness prior to cancer. The frequency with which these otherwise underlying death-related thoughts occurred varied among participants. Some reported increased regularity of these thoughts, while others indicated that the rate remained unchanged. Most

reported that, soon after diagnosis, a strong sense of self-preservation, or will to live, emerged. These women tended to react in one of two ways: task-oriented and emotion-based. For women who were more task-oriented, the goal was to organize their lives as much as possible through task-oriented lists or legal documentation so that their possessions would be appropriately distributed after their death. Imposing structure on their lives allowed the women to manipulate and manage the chaos that often ensues after cancer. This finding parallels studies that have found that cancer patients tend to use more problem-focused, adaptive coping in order to manage immediate priorities such as treatment decisions (e.g., Jim, Richardson, Golden-Kreutz, & Andersen, 2006). Conversely, participants who reacted emotionally relied more heavily on inner psychological strength as a way to ensure survival. These women used positive self-talk and “gut-level” feelings to gauge their own chances for survival.

Participants were able to articulate the processes (e.g., thoughts, feelings, and behaviors) and experiences they underwent as they were suddenly forced to manage this disruption to their lives. Although these processes were not consistent across all participants (see Table 3), the underlying goal appeared to be to successfully manage and integrate cancer (i.e., threat of death) into their lives. Participants noted thoughts, feelings and behaviors related to their families, friends, and community. Because cancer served as a reminder of mortality, for these women, the principal method for managing death anxiety was to engage in certain socially-sanctioned behaviors, essential to helping them create and maintain stability, personal identity, and meaning in a time of uncertainty. Such behaviors included engaging in interpersonal relationships, relying on

religion or spiritual beliefs and rituals, establishing a legacy, regaining independence, and continuing to participate in important family and social roles. By these very acts, by *living*, participants felt that they denied and defied death.

The basic message rooted in the participants' stories seemed to reflect their fear of becoming permanently physically helpless and dependent on others. For these highly active and vivacious women, the idea of being incapacitated in a dynamic world appeared to be the primary indicator that one was not living fully. Participants reported that being able to regain any increment of their physical abilities was a marker of fighting cancer and, perhaps unconsciously, death. Conceivably, the underlying realization was that dead things do not move and if one cannot move, one must be dead, literally or figuratively.

An example of this message was described by Susie:

I never thought I'd be able to get up and do and vacuum my floor and mop the floor and do dishes and stuff that I'm doin' now. It took me awhile, I haven't done that—I didn't do that in the beginning, but in the last several weeks I've been able to do my own house—light housework. And I never thought—and to go out to eat or anything—I never thought that I would be able to do that so that makes me feel better, gave me a better outlook if you understand what I mean.

Participants also reported the limits to what they would endure during the recovery process. More than half of the women spoke about their threshold, specifically the idea of unbearable pain and suffering, incapacitation, helplessness, and being a burden on the family. These factors help dispute the notion that pain alone causes individuals to wish for hastened death, an ongoing debate in the literature regarding terminally ill cancer patients (Wilson et al., 2000). For these women, when one was unable to participate in the world and see oneself as an integral part of it, life as they knew it would end, as a death to their unique spirit, long before the cancer proved to be

fatal. Thus, death became a viable alternative to enduring a body that would limit the freedom to live. This interpretation is similar to that of Mark Sullivan's (2004) article in which he theorized that based on findings from a number of death-related studies with terminally ill populations, individuals who wished for death were motivated more by an "intolerable anticipated future state" versus an "intolerable present state." In relation to participants in the present study, perhaps those who were able to visualize and anticipate how their lives would be as incapacitated individuals spoke about their thoughts on hastened death.

For participants, cancer served not only as a reminder of mortality but also as a major existential disruption to an individual's perception of the world as structured and predictable (e.g., Janoff-Bulman, 1989). However, a cancer diagnosis also allowed participants to reflect on the most cherished aspects of life: love, values, and a sense of freedom, dignity, and unique identity as a human being. In the cancer literature, this process is conceptualized as meaning making, whereby individuals attempt to reframe their cancer diagnosis to fit with their understanding of the world. Healthy psychological adaptation to cancer and outcomes of the meaning making process are typically viewed as posttraumatic growth, greater sense of meaning, and returned faith in a "just world" (Park, Edmonson, Fenster, & Blank, 2008). Although meaning making is generally thought to be a healthy process, it may only be of value if meaning is actually achieved (Park et al.). For the present participants, the integration process was not linear but rather a continuous one that changed over time. Studies have shown that this integration

process, or perhaps more accurately described as the reflection on existential meaning, may occur even 10 years post diagnosis (Bower et al., 2005).

Relation to Previous Research Findings

The majority of the findings from the present study are congruent with those from the existing literature on gynecologic cancer and cancer in general. These findings offer empirical support for findings from prior studies conducted across different cancer populations.

Employment and productivity were found to be important factors in facilitating emotional readjustment after cancer. For women who had been forced to lessen their work load or abstain from working all together, adapting to what they perceived as a less productive life proved to be psychologically difficult. Similarly, other studies have found employment to be a marker of control (Ferrell, Smith, Ervin et al., 2003) and important to quality of life and psychological health across cancer populations (Bellizzi & Blank, 2006; Bradley et al., 2006; Mellon, Northouse, & Weiss, 2006). International studies have also produced such findings (e.g., Kobayashi et al., 2008; Li & Lambert, 2007), illustrating the potential universality of the importance of employment or a feeling of productivity in maintaining quality of life for cancer patients.

In a related vein, many of the participants in this study reported decreased physical mobility due to cancer and treatment side effects as detrimental to their sense of independence and psychological well being. A 2005 study of women with ovarian cancer found that those who experienced greater physical impairment (e.g., difficulty engaging in household tasks) experienced greater distress, mediated by lower levels of perceived

control (Norton et al., 2005). Loss of physical mobility is also related to mood disorders such as depression (Stommel, Given, Osuch, Kurtz & Kurtz, 1993).

A number of studies have provided evidence for the psychological benefits of social support for a range of cancer patients, including those with lung cancer (Shell, Carolan, Zhang, & Meneses, 2008), breast cancer (Paskett et al., 2008), and bone marrow cancer (Kettmann & Altmaier, 2008). Not surprisingly, participants in the present study identified social support as a major component of the cancer recovery process. Defined as “relationships” in this study, the majority of participants cited the importance of having family, friends, and community members for emotional and physical support during cancer. A study by Ashing-Giwa et al. (2004) found this sentiment across four different ethnic groups of women diagnosed with cervical cancer. For these participants, social support was essential not only to quality of life but also to adherence to their medical regimens (Ashing-Giwa et al.). Conversely, unsupportive interactions, defined as perceived critical responses from family and friends, were related to lower quality of life as reported by ovarian cancer patients (Norton et al., 2005) and breast cancer patients (Figueiredo, Fries, & Ingram, 2004). Although quality of life was not specifically measured in the present study, one participant cited her continuous struggles with learning how to move forward in her life despite her family’s lack of social support. In addition to wanting support, participants in the present study also discussed the importance of giving support and reaching out to others in the community. This finding is consistent with prior research studies that find that females tend to respond

compassionately to individuals with physical disabilities (Hirschberger, Florian, & Mikulincer, 2005) and cancer (Mosher & Danoff-Burg, 2007).

Participants also expressed feelings of isolation, describing cancer as a lonely disease. The illness produces specific experiences that are difficult to fathom for those who have not experienced it directly. These findings mirror those found in cancer populations across cultures (e.g., Pelcastre-Villafuerte, Tirado-Gómez, Mohar-Betancourt, & López-Cervantes, 2007). Participants also described the unpleasant and sometimes unmanageable combination of side effects of chemotherapy that left them feeling debilitated and helpless, a phenomenon well documented within the cancer literature (Doyle et al., 2001; Ferrell, Smith, Cullinane et al., 2003; Ferrell, Smith, Ervin et al., 2003; Lakusta et al., 2001). Sexual side effects and sexual issues, common problems for gynecologic cancer patients, were not mentioned by the participants in this study. It is likely these issues did not seem relevant to the topic of interest.

Almost all of the women in the present study reported having some type of religious or spiritual beliefs and rituals to help them manage their concerns. One participant, who reported relying on a higher power as a way to cope, strongly believed that she had been destined to meet her current physician. She added that had she not been under the care of her physician, she would have missed the opportunity to participate in the clinical trial that, at the time of the interview, had completely eradicated her cancer. These findings corroborate studies that have shown the value of theistic beliefs for individuals with cancer. Following religious or spiritual principles allowed for patients to cope actively with their illness and report relatively high levels of overall well being

(Ashing-Giwa et al., 2004; Canada et al., 2006; Lauver, Connolly-Nelson, & Vang, 2007), even among terminally ill patients (Grumann & Spiegel, 2003).

An interesting finding of the present study was that even though the majority of the women cited the importance of religion in managing cancer, the process of integrating cancer into daily life involved relying more on tangible aspects of their lives, namely loved ones. In other words, although a relationship with God brings great comfort for some, it does not appear to surpass the benefits of relating with other human beings.

Although the small number of participants and disproportionate number of African American to Caucasian participants preclude any definitive statements, there was a small demographic difference in religiosity. Of the six Caucasian participants, half described themselves as “spiritual” or non-religious whereas all four of the African American participants described having strong religious beliefs. This was similar to Matsuyama, Grange, Lyckholm, Utsey, and Smith’s (2007) findings of differences in cultural perceptions about cancer in African American and Caucasian patients. Although both groups reported relying on religious beliefs as a coping mechanism, African American patients reported more overt religious beliefs than their Caucasian counterparts (Matsuyama et al.).

The qualitative nature of the present study allowed participants to elaborate on their religious or spiritual beliefs as well as to describe in their own words what these beliefs meant to them. For participants who identified themselves as religious, adhering to religious principles provided comfort, most notable from a reliance on an all-knowing and omnipotent god, a sense of predictability and control, and a prescribed life meaning.

These descriptions were congruent with the results of two other qualitative studies examining the ways in which hospice patients derive comfort from religion. Participants in both studies described the reassurance they felt from what religion offered them: life after death, control, and meaning (Ardelt, Ai, & Eichenberger, 2008; Pevey, Jones, & Yarber, 2008-2009). There was another similarity between the current study and the one conducted by Ardel and colleagues. The oldest and only non-religious participant in this study reported deriving overall satisfaction and meaning from knowing that she had lived a long and full life. Similarly, the Ardel et al. study showed that the older hospice patients, between the ages of 74 and 87, relied more on their age to gain a sense of meaning than religion.

Implications for Theory

The unique fusion of relatively new methodology (grounded theory), burgeoning area of research (existential psychology), and an understudied cancer population (gynecologic cancer) allowed me to explore uncharted research territory. Data analysis yielded a model that builds upon existential and psychological theories and is comparable to other models in the literature, particularly Terror Management Theory (TMT; Koole, Greenberg, & Pyszczynski, 2006; Pyszczynski, Solomon, & Greenberg, 2003). This study's model, grounded in participant data, illustrates the thoughts, feelings, and behaviors of women managing cancer as well as the psychological strain that inevitably comes with a serious illness.

Central to Becker's theory is the idea that humans participate in a "vital lie," deriving meaning from a shared set of created cultural beliefs. The category of

managing one's own awareness of mortality evident in the present study mirrors this concept. The subcategories of *legacy*, *relationships* and *religion* illustrate the specific structures participants used to fuse themselves to larger themes that give life meaning. This ability to attain symbolic and/or literal immortality in a time of uncertainty is a hallmark of Becker's theory. Some of the participants also spoke about their need for a personal project, such as volunteering in the community or finishing a photo album for the family. Again, this is similar to what Becker described as a *causa sui* project (i.e., immortality vessel) used to symbolically transcend death by leaving a personal mark on the world.

The main category of *cancer as a reminder of mortality* closely resembles the TMT (Koole et al., 2006; Pyszczynski et al., 2003) concept of mortality salience. Cancer appeared to be a primer for individuals to think about their own deaths. Cancer diagnoses also revealed participants' sense of self-preservation, a TMT assumption that humans have an innate instinct to live.

As noted previously, participants spoke about engaging in certain socially-sanctioned behaviors to derive meaning and purpose in life. Further, for these participants, engaging with the world and gaining meaning as a result allowed cancer to be integrated into their lives. This mirrors the TMT assumption that humans rely on culture to derive self-esteem as a way to buffer death-related anxiety.

The findings also support the first component of the death awareness continuum (Little & Sayers, 2004). Participants reported relying on social support from friends and family and cited the importance of giving back to the community either through volunteer

work or donating their bodies to science. These findings mimic the mortality salience aspect of Little and Sayers' continuum, thought by the authors to occur soon after diagnosis. According to these authors, reaching outward for support from friends and family marks this period, as does the desire to help other cancer patients. The sole focus for the patients and their loved ones at this stage is recovery.

The findings from the present study also address the limitations of the Little and Sayers study in that they had imposed predetermined categories on their participants in order to test the existence of a death awareness continuum. The present study found similar results despite the absence of predetermined categories, which suggests that, at the very least, the initial stage of the death awareness continuum holds some merit.

Little and Sayers (2004) also noted that cancer patients tended to leave this phase in order to enter death salience, generally around two years after diagnosis. Because one of the inclusion criteria of the present study was that participants could not be past two years post diagnosis, the remaining two stages of the death awareness continuum, death salience and dying salience, were not examined. This is an interesting area of research that could be further explored through the use of qualitative methodology.

This study also provides support for components of logotherapy, a therapy model created by holocaust survivor Viktor Frankl. In his (1962) memoir, *Man's Search for Meaning*, he documents how his struggles as a prisoner during World War II informed his therapeutic approach. The basic tenets of logotherapy are: (1) "life has meaning under all circumstances, even the most miserable ones"; (2) "our main motivation for living is our will to find meaning in life"; and (3) "we have inalienable freedom to find

meaning in what we do, and what we experience, or at least in the stand we take when faced with a situation of unchangeable suffering” (Viktor Frankl Institute of Logotherapy, n.d.).

Further, according to Frankl, the ways in which individuals can find meaning are achieved by: (1) “creating a work or doing a deed,” (2) “experiencing something or encountering someone,” and (3) “the attitude we take towards unavoidable suffering” (Viktor Frankl Institute of Logotherapy, n.d.). Participants in this study voiced their desire to continue engaging in the world to gain feelings of productivity, familiarity, and love. According to logotherapy principles, this engagement illustrates the intense, purposeful process that human beings undergo as a way to create meaning in dire circumstances. In general, participants attained meaning in the face of cancer through ways similar to those Frankl theorized. Specifically, participants created a personal project, similar to Becker’s notion of a *causa sui*; acknowledged the frailty and uncertainty of their existence via cancer; and managed the cancer experience based on individual style and cultural beliefs and values. Further, the limitations of self-preservation described by most of the women in this study illustrate the human craving for dignity and identity. One participant, Jennifer, when describing what she perceived to be her purpose in life, stated,

We all have a purpose and sometimes you don’t even know. Some people don’t know, “Okay, what in the world am I here for?” It’s not just to wake up every day and die one day. There’s something that only each person can do. Every person is unique and only they can only do certain things.

For Frankl, this attitude was essential to survival, particularly in the darkest moments of his existence. He writes poignantly about the unique contribution and irreplaceable nature of each human being:

His work could not be done by anyone else, any more than another person could ever take the place of the father in his child's affections. This uniqueness and singleness which distinguishes each individual and gives a meaning to his existence has a bearing on creative work as much as it does on human love. When the impossibility of replacing a person is realized, it allows the responsibility which a man has for his existence and its continuance to appear in all its magnitude. A man who becomes conscious of the responsibility he bears toward a human being who affectionately waits for him, or to an unfinished work, will never be able to throw away his life. He knows the 'why' for his existence, and will be able to bear almost any 'how' (pp. 126-127).

The existential crises that participants in this study faced and the ways in which these crises were managed may also be situated within components of Erik Erikson's (1959) stages of psychosocial development. First, the present model bears similarities with Erikson's middle adulthood stage: generativity versus stagnation. Participants continuously stressed the importance of productivity and feeling as if one had a duty to contribute to society. For these women, when the limits of physical mobility prevented them from fully engaging in productive activities, they felt helpless and useless—similar to what Erikson would describe as stagnation.

Resolving this crisis in a cancer population proves to be tenuous. The way in which participants generally addressed this crisis was to regain physical mobility slowly, an outcome not always achievable for individuals with a serious illness. Second, with the mean age of participants around 63 years of age, their experiences also resembled the last stage in Erikson's model psychosocial crisis prominent in late adulthood: ego integrity

versus despair. Participants were forced, prematurely for some, to examine their lives even more intensely as a result of cancer.

According to Erikson, individuals in this stage tend to ask the fundamental question of “What kind of life have I lived?” Most of the participants reported being able to incorporate both positive and negative aspects of their lives, which, based on Erikson’s model, is essential to developing a healthy attitude about death. In sum, components of Erikson’s model were supported by this study; however, the present model suggests that individuals face certain stages of psychosocial development not as a result of age alone but as a combination of age and life experiences that might sometimes precipitately force them to face and resolve psychosocial crises.

An underlying theme of the study was the participants’ desire to maintain their own sense of identity despite having a cancer diagnosis. This finding adds support to Baumeister and Leary’s (1995) belongingness hypothesis where the fundamental motivation for human behavior is to gain a sense of belonging through interpersonal relationships. In other words, human beings regulate their behaviors and identify their position in the world via culture and social contexts (Breckler & Greenwald, 1986). Although this belongingness theory varies from Becker’s model and TMT in that the underlying motivation is the need to belong and not death anxiety, the common ground is the necessity of culture in helping individuals derive self worth, self-esteem, and safety. Simply put, all human experience is contextual. Brewer and Gardner’s (1996) organization of the levels of the self, based on theories of self representation, attachment, and belongingness, as well as Bronfenbrenner’s (1979) ecological model lend themselves

well for organizing the present findings at various levels (see Figure 1): group (e.g., religion), interpersonal (e.g., relationships), and individual (e.g., independence).

In sum, the present study findings are consistent with the results drawn from prior social science theories and provide a more comprehensive understanding of the gynecologic cancer experience. Findings from this inquiry parallel those from previous cancer studies investigating individuals' need for social support, religion, and identity.

A unique contribution of this study is the explanation of the nature and function of specific processes utilized by women with gynecologic cancer to enhance personal meaning and integrate cancer into daily life. In other words, this study provides a conceptual understanding of the gynecologic cancer experience. Further, the present findings offer an additional layer to components of existing theories and models, including those in existential psychology (e.g., TMT) and self psychology (e.g., Baumeister & Leary, 1995).

Implications for Research

Findings from this study may be used as a foundation for future studies to formulate new questions related to death anxiety or to conduct inquiries on the concept of managing existential issues related to chronic disease.

This study presents a theoretical framework within which to understand the ways that women with gynecologic cancer manage death anxiety in the face of their diagnosis. The focus of this study was to examine the methods individuals use to minimize death anxiety. For future qualitative studies, it may be important to gather information on how individuals with cancer understand death and what this concept means to them. For example, questions I would consider are: "What is death?", "How would you describe

death?” “What is immortality?”, and “What do you think happens to you after you die?” Findings from this type of study could be beneficial for clinicians or mental health professionals working in medical settings to better understand their patients’ views on their disease, coping mechanisms, and cultural beliefs, all factors that may play a role in treatment and overall quality of life.

The present study yielded 5 categories and 8 subcategories that comprise a theoretical model of how death anxiety is managed in a gynecologic cancer population. These categories and subcategories could be explored further in future studies. For example, the subcategory of *relationships* could be investigated on a deeper level by interviewing patients as well as their loved ones to understand the interpersonal dynamics behind the cancer experience.

The focus could also be on the family culture of death, how death is viewed, and how death is managed within a family system. I noticed that several participants had a friend or family member with them during their clinic appointment, a seemingly common practice that would have made a family-focused study possible. In addition, these categories and subcategories as well as findings that were not included in the present results could be utilized to develop a gynecologic cancer-specific questionnaire for future quantitative studies. This questionnaire could focus on certain areas such as gynecologic cancer-specific symptoms and fear related to daughters’ health.

A longitudinal design might be able to capture more fully the experience of managing death anxiety. Studies show that death anxiety tends to decrease over time, particularly for cancer patients post 2 years diagnosis (Cella & Tross, 1987; Sigal et al.,

2008). This decrease has typically been demonstrated using brief death anxiety questionnaires; however, it would be interesting to examine via interviews the personal factors that contribute to reduction in death anxiety for individuals with cancer.

Although qualitative studies do not aim to generalize findings, a broader range of women with gynecologic women could be recruited for future studies based on ethnicity, age, and religious or spiritual background. It would also be interesting to recruit a sample from a different cancer population, perhaps one unique to male cancers (e.g., testicular, prostate) or other chronic illnesses such as organ transplant patients. Further, the interview questions used in this study could be tested to examine their efficacy in gathering rich, nuanced information related to the research question. Because the concept of death anxiety is thought to be universal, it would also be fascinating to investigate this phenomenon in other countries.

Study methods. The present study provides methodological strategies for recruiting participants and conducting interviews, illustrating the feasibility of this type of qualitative inquiry. For this study, the key to success in recruiting medical participants was to form relationships with certain members of the target clinic. I contacted one of the two attending physicians at the Ob-Gyn clinic at the cancer center. Initial contact with the attending physician provided the opportunity to explain the purpose of the study as well as learn about the logistics of the clinic and the patient population. Further, she was able to put me in contact with medical staff members who could assist with recruitment. By initiating and maintaining contact with clinic staff, I was able to increase my visibility during clinic days and successfully recruit participants within a targeted

time period. In addition, the nurses were able to recommend patients who met study criteria. Also, having nurses as an initial contact point for patients during recruitment increased the likelihood of participation due to the level of familiarity between patients and staff.

Another important recruitment strategy was my actual presence during clinic days. Prior experience has shown that patients are not likely to respond to flyers, handouts or word-of-mouth advertisements about a study. An initial in-person introduction of the researcher to potential participants was crucial because I was able to explain the purpose of the study, obtain consent if the patient agreed to participate, and begin the interview while the patient waited for her physician.

As noted in Chapter Three, theoretical sampling was conducted near the completion of data analysis as a way to address any questions or gaps in the data as well as to check in with participants to ensure that the present study's findings accurately reflected their cancer experience. I was able to successfully contact by phone three of the six available participants who had agreed during the informed consent to participate in this checking-in process. I briefly summarized the study's findings using a phone script (see Appendix D) and encouraged each participant to provide any feedback. Although this theoretical sampling technique was utilized to ensure credibility (i.e., internal validity) of the present findings, there are several factors that would have strengthened this process: (1) an in-person meeting to discuss study findings, (2) the availability of a copy of the categories and subcategories for participants, and (3) an opportunity for participants to agree, disagree, and provide constructive feedback on the findings. Future

researchers are encouraged to consider these factors to ensure that the process of theoretical sampling is conducted in a rigorous manner.

A key factor to highlight is that the researcher is female. Thus, I may have had success in recruiting gynecologic cancer patients largely based on my gender. Because gynecologic cancer is a uniquely female disease participants may not have been as comfortable discussing their experiences with a male researcher. Most notably, this study demonstrated the feasibility of conducting a study on a sensitive topic such as death. Recommendations have been made for researchers wanting to carry out studies that explore such sensitive topics (see Casarett & Karlawish, 2000).

Researchers who choose to explore these areas should be equipped with the skills necessary to manage these discussions. Qualitative inquiry, particularly face-to-face interviewing, requires a baseline level of interpersonal skills that allow the researcher to build rapport and trust with participants in order to explore in-depth the phenomenon under question. Therefore, at minimum, the researcher should learn basic interviewing skills to conduct interviews in a professional manner. In addition, it would be important for the researcher to be able to recognize any potential ethical issues that may arise during the interview process, such as participant distress. It is important when conducting in-person interviews that key elements of this process are fully recognized, understood and respected.

Implications for Practice

This theoretical model holds implications for professionals and trainees in a range of helping professions as well as for loved ones of those suffering from cancer.

Relevance to professionals and trainees. Health psychology is a burgeoning area for research and practice as psychologists are increasingly asked to inhabit roles as members of multidisciplinary teams in medical settings. Health psychologists use their expertise to implement bedside interventions; conduct cognitive, personality, and neuropsychological evaluations, and provide outpatient psychotherapy for patients who are struggling with the psychological aspects of their disease.

A relatively new area within health psychology and behavioral medicine is pre-surgical psychological evaluations (PPE), a tool based on Loeser's biopsychosocial model (1982). This approach is used to identify and minimize risk factors known to be associated with poor surgical outcome. Andrew Block's (1996) comprehensive text on conducting PPEs in chronic pain populations provides an overview of the leading psychological risk factors (e.g., personality, cognition) and medical risk factors (e.g., obesity, chronicity of pain complaints), based on empirical data, shown to predict surgical prognosis. Block's text also offers specific guidelines on conducting PPEs, developing working relations with the referring physician and medical staff, and psychological treatment recommendations. Although PPEs have been primarily conducted with spine surgery patients, it may be useful to implement this type of evaluation to assess for risk factors for how oncology patients may respond to surgery or other invasive treatment procedures. Findings from the present study offer initial empirical support for the types of psychosocial factors found in a cancer population that may affect treatment outcome. These factors include adequate social support, healthy coping mechanisms (e.g., spiritual or religious beliefs), and level of physical mobility.

For trainees, including medical and health psychology students, having awareness of issues that typically arise for cancer patients would be beneficial. Based on findings from this study, there are several areas that would be particularly relevant for training purposes. First, it would be important to relay to students and trainees that many individuals with cancer use religion and/or spirituality as a coping mechanism, and to convey the importance of respecting individual beliefs even if one's own differ fundamentally. Second, cancer can be a tumultuous experience on a physical, psychological, and social level. Students and trainees also should be taught that the degree of disruption cancer causes varies by each individual and thus, one should not expect patients to behave in certain ways. This also means that any psychologically-based interventions for patients should be tailored based on patient needs. Third, training should emphasize allowing patients to maintain their dignity whenever possible and how important this is for someone who may feel as if he or she has lost control over many aspects of his or her life. Last, social support has been shown repeatedly to play an instrumental role in helping patients manage their disease. Therefore, trainees should be prepared to offer resources or support for patients when needed or, at minimum, alert a supervisor if patients voice the need for additional or professional support. By teaching students in key points about the cancer experience could learn to better recognize and manage clinical issues they may face during their clinical training. In addition, practitioners at various levels of experience should be provided resources or training on how to have conversations about death with their patients. As illustrated in the present study, individuals with cancer do think about their mortality, regardless of disease stage

and prognosis. Given that the opportunity for patients to disclose their cancer-related concerns to others is related to overall well-being (Figueiredo et al., 2004), it is critical that patients are provided space to express their feelings, including death-related thoughts, without fear of judgment or shame.

Relevance to families and friends. The cancer experience, as demonstrated in this study, is not a linear one. Participants reported experiencing an array of thoughts and emotions related to managing their disease. For loved ones, this cyclical process may seem overwhelming and confusing to contain. At times, the mere presence of a loved one served as a protective factor for participants. Many of these women noted how much comfort they received by having family or friends also attend clinic appointments or treatment days, an example of how loved ones do not have to do but simply be.

It is also important to note that despite the taboo nature of death, all of the participants reported that they had thought about their own death at some point after their diagnosis. These women were also candid in talking about their thoughts and feelings related to death. Therefore, one should not assume that loved ones with cancer have not thought about the possibility of dying or would not be comfortable talking about existential issues. Of course, each individual differs in his or her level of comfort in discussing these issues and should be met at his or her comfort place. In a related vein, because the cancer experience varies by individual, loved ones should be aware of holding expectations of how the individual will or will not behave as a result of cancer. As this study has shown, the experience of integrating cancer into one's framework (i.e.,

deriving meaning from their diagnosis) is a cyclical, continuous, and very *personal* process. Therefore, how individuals adjust to their diagnosis is likely to vary greatly.

It is well documented that the effects of cancer are not limited to the patient. Studies show that caretakers themselves also experience psychological distress and physical effects related to the caretaking role (e.g., Holland, 1992; Tomarken et al., 2008). A variety of national resources can be found online such as through the American Cancer Society (www.acs.org) and National Cancer Institute (www.cancer.gov). For Virginia residents, help and support for cancer patients as well as their caregivers can be found at www.virginiacancer.com/supportgroups.asp.

Conclusion

This interpretive grounded theory study was designed to answer the following research question: “What are the experiences and processes by which women with gynecologic cancer construct meaning and manage death anxiety in the face of their cancer diagnosis?” Ten women diagnosed with gynecologic cancer were recruited from an urban cancer center and interviewed using a semi-structured interview guide. The data analytic process was informed by specific grounded theory techniques such as line-by-line coding, focused coding, and memo-writing. Feedback from two graduate student auditors and the participants themselves were also incorporated into data interpretation. The result was a theoretical framework in which to understand how women diagnosed with a potentially life threatening illness such as cancer managed such a diagnosis.

The main categories found grounded in the data were: (1) cancer as a reminder of mortality, (2) self-preservation, (3) managing awareness of one’s own mortality, (4)

dignity overrides self-preservation, and (5) integration of cancer into life. This theoretical framework shows the physical, social, and psychological components of having cancer, illuminating the complex nature of the cancer experience. This model, based on participant data, offers a comprehensive picture of the gynecologic cancer experience and holds theoretical, research, and practical importance.

Findings from this study illustrate the participants' remarkable demonstration of adaptability and resiliency during cancer. In writing this manuscript, I hoped to have accomplished several things. First, I hoped that I would bring the gynecologic cancer population more exposure and pique scholarly interest for future studies with this fascinating group of individuals. Second, I hoped that I was able to illustrate more of the underlying processes of cancer as well as the behaviors that manifest as a result. Third, I also hoped to gain greater self-awareness through the intensive data collection and analysis process of understanding meaningful aspects of people's lives, which I feel I did. And last, I hoped that I would be able to share with the reader a deep, reflective understanding of the cancer experience through the voices of people who had lived it.

Final Thoughts

Sadly, as noted earlier in Chapter 3, two of my participants died before the completion of this manuscript. In addition, another participant had been transferred to hospice care. The news about these three women affected me deeply and continues to do so today. I wrote an entry in my reflexive journal, partly out of habit and partly to purge some of the swirling thoughts in my head. I decided not to include this entry in any of the chapters because I wanted to find a respectful way to highlight these three women and, for me, this meant separating them from the research component as much as possible. This entry is dated March 25, 2009. I wrote:

Today, I called the clinic to touch base about the status of the health of my participants before making follow-up phone calls. Despite knowing the severity and mortality rates of gynecologic cancer, I was stunned to hear from one of the nurses that two of my participants had died and that one was in the care of hospice. My reaction to the news callously exposed my own elaborate death-denying system. I realized that I had unconsciously assumed that my study served as a buffer against death, as if willingness to talk about death somehow protected my participants from it. I cried when I came to grips with the fact that this was only my illusion. Part of me thought that by increasing my knowledge in existential psychology and spending hours researching death anxiety for my study, I would build a protective shell, that I might not take death so hard. But I can't intellectualize death. At the core, acknowledging and accepting death is very much an emotional process.

My thoughts immediately drifted over to my interview experiences with Lula, Lucille, and Jennifer, and how I was able to quickly form bonds with them throughout the course of the interview. There is no room for small talk when discussing death. I remember meeting Lucille's daughter, admiring Lucille's new wig, and marveling over her matter-of-fact and no nonsense attitude about old age, cancer, and dying. I can recall Lula and her friend, "Ann," who came with Lula to every single chemotherapy appointment. When describing friends, Lula had said Ann was "the best." And Jennifer. The youngest participant at 39, her situation saddens me the most. Lively and good humored, I can't picture her as a hospice patient, sick and weak, waiting for her last breath. During our interview, she told me that given her age and prognosis, she didn't believe that the threat of mortality would be an issue.

Certain quotes have started to haunt me. Lucille had said, “You know something is going to take me away...and maybe it’s going to be this.” I think about Lula and how she repeatedly stated that if God called her up to heaven, she would be prepared to go. “If He was to call me today, I would be ready,” she said. I can’t help but think about Lucille and Lula’s last thoughts. Did they feel as if they had lived meaningful lives? Were they surrounded by their family and friends? Did Lula feel any sense of joy as she thought about leaving her physical body to be with God and loved ones who had gone on before her? I wonder what Jennifer thinks about. Does she still pray? Does she feel like she was able to reach out and touch others in the way that she had planned? These are questions I’ll never know the answers to. I can only hope that the last days of Lucille and Lula’s lives were shared with those that they loved. And for Jennifer, I wish she could know that I am one of the ones she has touched.

Table 1

Selected Characteristics of Participants

| Name | Age | Race ^a | Religious Affiliation | Year of Diagnosis | Cancer Type ^b and Stage | Education ^c Level | Relationship Status | Cancer Recurrence |
|----------|-----|-------------------|-----------------------|-------------------|------------------------------------|------------------------------|---------------------|-------------------|
| Lula | 66 | C | Methodist | 2007 | O I | H | D | Yes |
| Lily | 59 | C | Catholic | 2007 | E II | SC | M | No |
| Lucille | 80 | C | Baptist | 2008 | O IV | H | W | No |
| Susie | 77 | C | Lutheran | 2008 | O III | SC | W | Yes |
| Molly | 61 | C | Protestant | 2007 | O III | H | W | No |
| Faith | 51 | AA | Baptist | 2007 | O | C | M | No |
| Jennifer | 39 | AA | Christian | 2006 | E | C | M | No |
| Susan | 71 | AA | Baptist | 2007 | E IV | H | W | No |
| Jean | 68 | AA | Baptist | 2008 | E I | G | M | No |
| Rebecca | 60 | C | Episcopalian | 2006 | E III | SP | M | No |

Note. ^aRace: AA = African American; C = Caucasian. ^bCancer type: O = Ovarian cancer; E = Endometrial/uterine cancer. ^cEducation level: G = 8th grade or less; H = High school or GED; SC = Some College; C = College graduate; SP = Some post-graduate education. ^dRelationship status: M = Married; D = Divorced; W = Widowed.

Table 2

Categories and Subcategories

- A Category Cancer as a reminder of mortality:** This category reflects how receiving a cancer diagnosis served as a reminder of one's own mortality.
- B Category Self-preservation:** This category illustrates the innate human instinct to live after receiving potentially life threatening news (i.e., cancer diagnosis). Individuals typically reacted in two ways in order to preserve life; these reactions allowed them to *minimize* (e.g., remove from consciousness) thoughts about one's own death.

The word "reaction" was used based on its definitions as "a response to some treatment, situation, or stimulus" and "an action induced by vital resistance to another action" (Merriam-Webster OnLine, n.d.). Further, in this study, task oriented and emotion-based reactions are temporally distinct from the category of "managing awareness of one's own mortality." Participants typically spoke of these reactions as occurring soon after receiving a cancer diagnosis whereas the actions defined by the latter category occurred throughout the cancer experience.

- 1 Subcategory Task-oriented reaction:** is defined as the immediate focus on the concrete and tangible aspects of managing cancer following a cancer diagnosis. Being able to manipulate these tangible aspects allowed participants to perceive themselves as having control, increase chances of survival, and distract themselves from the severity of having cancer. Participants reported organizing paperwork (e.g., living will), gathering information on cancer, and creating treatment-related task lists.
- 2 Subcategory Emotion-based reaction:** is identified as the immediate focus on the internal arousal of specific feelings and emotions following a cancer diagnosis. Participants reported sensing gut-level feelings and the urge to gather emotional strength. Although some emotion-based reactions contained religious themes, this subcategory is temporally and qualitatively distinct from the subcategory of *religion*. The latter category reflects a more long-term coping mechanism that is utilized throughout the cancer experience.

- C Category Managing awareness of one's own mortality:** This category reflects the necessity of engaging in certain socially sanctioned-behaviors to receive a sense of dignity and personal identity when faced with mortality. Engaging in these behaviors not only gives individuals a sense of dignity and identity that allows one to fight symbolically and/or literally against death, but also allows individuals to derive a sense of meaning and purpose in life.

- 1 Subcategory Relationships:** This subcategory illustrates the function of family and friends as part of the cancer experience.

- 2 **Subcategory** *Religion*: This subcategory reflects the use of religious beliefs as a way to find meaning in cancer and security from imminent death. Included in this subcategory are the concepts of immortality (e.g., soul never dies) and heaven, a predetermined time on earth, the power of God, and cancer as a “lesson” from God (e.g., highlight a blind spot).
 - 3 **Subcategory** *Belief in a higher power*: This subcategory focuses on the use of spiritual beliefs, without overtly religious undertones, as a way to find meaning in cancer and security from imminent death. This concept includes the feeling that events and occurrences were aligned for a reason by a higher power, such as meeting their current physician or being accepted into a certain clinical trial.
 - 4 **Subcategory** *Leaving a legacy*: This subcategory illustrates ways of establishing one’s personal mark on the world. This was accomplished through passing on a family legacy (e.g., being remembered in a certain way), engaging in community outreach, and donating one’s body to science.
 - 5 **Subcategory** *Independence*: This subcategory highlights the importance of establishing a sense of freedom and independence as a way to maintain one’s identity through productivity. This was exemplified by certain behaviors (e.g., being able to live alone, run errands) and feelings (e.g., sense of self-efficacy).
 - 6 **Subcategory** *Importance of roles*: This subcategory consists of the necessity of maintaining and engaging in certain traditional family, social, and community roles as ways to maintain one’s identity and derive meaning from life. Examples include providing for the family and participating in uniquely personal activities such as a hobby.
- D Category** *Dignity overrides self-preservation*: This category focuses on the personal line drawn between fighting for survival and accepting death as a reality. Death as a way to avoid prolonged incapacitation, helplessness or suffering, states of being that would strip individuals of their dignity and inflict pain on their loved ones, typically overrode self-preservation. For individuals, these states of being would prevent them from engaging in necessary socially-sanctioned behaviors. Because these behaviors serve a dual purpose (fights death symbolically/literally as well as give individuals a sense of meaning and purpose in life), not being able to fully function would diminish their sense of dignity and identity. Thus, the individual’s level of self-preservation decreases.
- E Category** *Integration of cancer into life*: This category reflects the outcome of managing a cancer diagnosis through the mechanisms described above. By engaging in meaningful interactions, individuals are able to minimize their death-related thoughts and integrate cancer into their lives in order to continue with daily living.

Table 3

Participants within Each Category and Subcategory

| Category/ Subcategory | Lula | Lily | Lucille | Susie | Molly | Faith | Jennifer | Susan | Jean | Rebecca |
|----------------------------------|------|------|---------|-------|-------|-------|----------|-------|------|---------|
| Cancer as a reminder | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Problem-focused | No | Yes | No | Yes | No | Yes | No | No | Yes | No |
| Emotion-focused | Yes | No | Yes | No | Yes | No | No | No | Yes | No |
| Relationships | Yes | Yes | No | Yes | Yes | No | Yes | Yes | Yes | Yes |
| Religion | Yes | No | No | Yes | Yes | Yes | Yes | Yes | Yes | No |
| Higher power | No | Yes | No | No | No | No | No | No | No | Yes |
| Legacy | Yes | Yes | No | Yes | Yes | Yes | Yes | No | No | Yes |
| Independence | No | No | Yes | Yes | No | Yes | Yes | Yes | Yes | No |
| Roles | No | Yes | Yes | No | Yes | Yes | Yes | No | Yes | No |
| Dignity | Yes | Yes | Yes | Yes | No | No | No | No | Yes | Yes |
| Integration | No | No | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes |

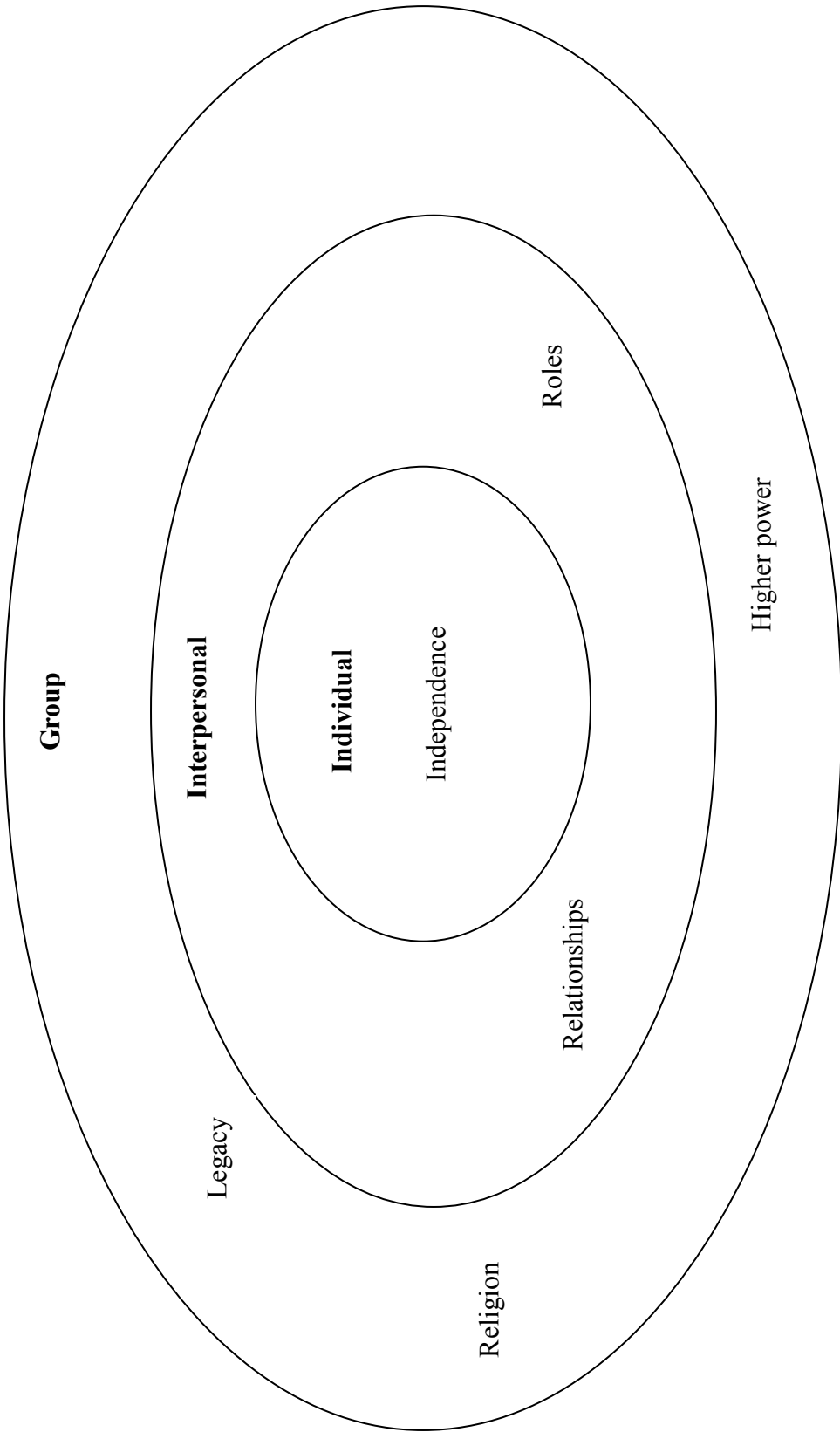


Figure 1. Model of Managing Death Anxiety.

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APPENDIX A
DEMOGRAPHIC QUESTIONNAIRE

Code _____

Please provide the following background information about yourself.

1. Today's date: _____
2. What is your date of birth? _____
3. What is your race? _____
4. What is your ethnicity? _____
5. What is your religious or spiritual affiliation? _____
6. When were you diagnosed with cancer? Month _____ Year _____
7. With which type of cancer and what stage were you diagnosed?

8. What types of treatment have you received or are currently receiving for cancer?
(Check all that apply)
 - Chemotherapy
 - Radiation
 - Surgery
 - Other _____
9. Have you had any previous cancer diagnoses?

10. Who is your physician here at Massey Cancer Center?
 - Dr. Cecelia Boardman
 - Dr. Weldon Chafe
11. Do you have any other major medical conditions? _____

12. How much formal education have you had?
 - 8th grade or less
 - Some high school or trade school
 - High school graduate or GED
 - Some college

- College graduate
- Some post-graduate education
- Post-graduate degree

13. What is your current relationship status?

- Single
- Married
- Divorced
- Separated
- Partnered or in a significant relationship
- Widowed

14. Do you have children? If so, what are their ages? Do they live at home with you?

15. What is your employment status?

- Employed full or part-time–Actively working as a(n) _____
- Employed full or part-time–Currently not working, worked as a(n) _____
- Disabled or applying for disability
- Retired as of _____

16. Do you have any health insurance?

- Private insurance
- Medicaid
- Medicare
- Indigent/No insurance
- Other _____

17. What is your zip code and city of residence? _____

18. Has anyone in your household been sick in the past year? If so, were you the caretaker?

19. What other experiences have you had with cancer (with friends, family members, etc.)?

APPENDIX B
PARTICIPANT CONSENT FORM

TITLE: Understanding Death Anxiety in Women with Gynecologic Cancer

VCU IRB NO.: 11753

PRINCIPAL INVESTIGATOR: Kathleen M. Ingram, J.D., Ph.D.

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

PURPOSE OF THE RESEARCH PARTICIPATION

The purpose of this research study is to explore and better understand the experiences of women with gynecologic cancer. Part of this experience might involve thoughts and feelings related to death or mortality women may have about facing a potentially life threatening diagnosis such as cancer. You are being asked to participate in this study because you are a woman who has been diagnosed with gynecologic cancer.

DESCRIPTION OF THE RESEARCH AND YOUR INVOLVEMENT

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

In this study you will participate in an interview that will last approximately one hour. During this interview, you will meet with one interviewer and you will be asked to talk about your experiences with cancer, your feelings about life and death issues related to cancer, and how you deal with a life threatening diagnosis.

The interview will be audiotaped so we are sure to get all of your ideas, but no names will be used. If your name is recorded by accident, we will remove any names or potentially identifying information when the study staff transcribes (types up) the interviews.

After the interview, the interviewer will ask permission to contact you by telephone or mail to ask you some follow-up questions. That follow-up will take place 1-3 months after your interview.

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

RISKS AND DISCOMFORTS

Sometimes talking about these subjects causes people to become upset. Several questions will ask about things that have happened in your life that may have been difficult. You do not have to talk about any subjects you do not want to talk about, and you may stop the interview at any time. If you become upset, the study staff will give you names of counselors to contact so you can get help in dealing with these issues.

BENEFITS TO YOU AND OTHERS

You are not expected to get any direct benefit from this study, but the information we learn from participants in this study may help increase our understanding of the important issues women with gynecologic cancer might face.

COSTS

There are no costs involved in participating in the study other than the amount of time it will take to fill out a questionnaire and participate in the interview process.

ALTERNATIVES

There are no other ways to participate in this study.

CONFIDENTIALITY

Potentially identifiable information about you will consist of surveys, audiotapes of interviews, and transcripts of interviews. This information is being collected only for research purposes. Your data will be identified by ID numbers and pseudonyms (fictional names) and stored in a locked research area. All personal identifying information (names, addresses, and phone numbers) will be kept in password protected files and these files will be deleted after the study has been completed. Interview audiotapes and questionnaire data will be kept in a locked file cabinet until the study has been completed and will be destroyed at that time. Interview transcripts with no identifying information will be kept indefinitely. Access to all data will be limited to study personnel.

The interviews will be audiotaped, but no actual names will be recorded. At the beginning of the session, you will be asked to use a pseudonym only so that your actual name is not recorded. The tapes and the notes will be stored in a locked cabinet and destroyed after the completion of the study.

We will not tell anyone the answers you give us; however, information from the study and information from the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University. What we find from this study may be presented at meetings or published in papers, but your name will not

ever be used in these presentations or papers. In addition, if you tell us that you are intending to hurt yourself or someone else or if you tell us about abuse of a child or elderly person, we are required to report this information to the authorities.

IF AN INJURY HAPPENS

Virginia Commonwealth University and the VCU Health System (also known as MCV Hospital) do not have a plan to give long-term care or money if you are injured because you are in the study. If you are injured because of being in this study, tell the study staff right away. The study staff will arrange for short-term emergency care or referral if it is needed. Bills for treatment may be sent to you or your insurance. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions;
- the investigator has stopped the study; or
- administrative reasons require your withdrawal.

QUESTIONS

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

HaNa Kim, M.S.
Virginia Commonwealth University
612 N. Lombardy St., Room 203
P.O. Box 842018
Richmond, VA 23284-2018
Email: kimh9@vcu.edu

Kathleen Ingram, J.D., Ph.D.
Virginia Commonwealth University
806 W. Franklin St.
P.O. Box 842018
Richmond, VA 23284-2018
Ph: 804-828-6346

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

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

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

CONSENT

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

| | | |
|--------------------------|-----------------------|------|
| Participant name printed | Participant signature | Date |
|--------------------------|-----------------------|------|

Name of Person Conducting Informed Consent Discussion / Witness name printed

| | |
|---|------|
| Signature of Person Conducting Informed Consent / Witness | Date |
|---|------|

| | |
|--|------|
| Investigator signature (if different from above) | Date |
|--|------|

APPENDIX C
INTERVIEW GUIDE

Introduction, purpose of interview, confidentiality

The participant will be informed about the purpose of the interview and the topics that will be covered, and will be assured about the confidentiality of all information discussed.

Thank you for agreeing to meet with me. The main purpose of this research study is to better understand the ways women like you think and feel about mortality in relation to having cancer. Obviously this subject matter is very powerful and personal in nature. I want to let you know how privileged I feel that you are willing to share this information with me. If our conversation becomes too upsetting for you at any time, do not hesitate to stop me. You have the right to stop and/or withdraw from this study at any point.

Let's go over the consent form so that you can fully understand what is being required of you today. Please stop me at any time if you have questions.

If you give me your permission to use this information, please sign this page and keep the rest of the form. Do you have any questions before we start? I expect that this interview will last around 1 hour. Again, you can pause or stop the interview any time you wish.

The interview will then proceed with soliciting information about ideas, concepts, and issues in the following areas:

Questions and probes

- As you sit here today, what immediate thoughts do you have when you think about having cancer?
 - What immediate feelings and emotions do you have when you think about having cancer?
- Before your cancer diagnosis, did you ever think about the possibility of your own death?
 - If so, what kinds of thoughts did you have?
 - What kinds of feelings did you have about it?
- What are your thoughts about your own survival and mortality?
 - What feelings do you have when you think about this?
- How do your current thoughts about the possibility of your own death compare to the kinds of thoughts you had before being diagnosed with cancer?
 - How do you feel when you think about this?
 - What do you do with those thoughts and feelings?
- What gives you hope or strength during this time?

Closure

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

Thank you for sharing your feelings and thoughts with me today. As I mentioned at the beginning of the interview, you will not be identified in any way with the information you have given me.

If you need to contact me or other individuals involved in this project, please use the contact information given in the consent form.

APPENDIX D
PHONE SCRIPT

Phone Script for Follow-up Call with Participants

Introduction: Hello, Ms. [*participant name*]. My name is HaNa Kim and I am a student at VCU. Last [*month*], we met for an hour at the Dalton Clinic at Massey Cancer Center so I could interview you for a study I was conducting. At the end of our interview, I asked you for your phone number so I could contact you if I had any further questions about your story. I'm calling you today because I am in the analysis phase of my study. The type of analysis I'm conducting allows me to check in with participants about how well the results I have found fits with their contributions. Would you be willing to spend a few moments with me over the phone to discuss the results of my study? I would love to receive any feedback you have for me.

"No": Okay. I really appreciate your time. If you have any questions for me, please feel free to contact me. [*Give contact information.*]

"At another time": Great. When would be a good time to call you back?

"Yes": Great. As you remember, the purpose of my study was to understand the experiences of women diagnosed with gynecologic cancer. I also asked you to help me understand how you felt about death as a result of your cancer diagnosis. Based on interviews with you and 9 other women with gynecologic cancer, this is what I've found.

I found that participants wanted to live a meaningful and dignified life and that cancer served as a reminder to participants of the most cherished aspects of their lives, namely family, friends, community, religion, and preserving their own identity. By being able to think about these aspects, reflect on them, and actively engage with loved ones, women were able to successfully integrate cancer into their lives. I also found that this was not a linear process, meaning women didn't move from one stage to another. Rather, it was more continuous. And although there were similarities in the ways women managed cancer, some aspects were more important to some than others, such as religion or giving back to the community. Do you have anything you would like to add to what I've just said or things I should consider that I missed?

End: Thank you so much for taking the time to talk with me. Your contributions have been so important to the process of this study. If you would like to meet in-person during your next appointment at Massey to further discuss the results, I'm more than happy to do so. Again, thank you for contributions to this study.

APPENDIX E
AUDIT TRAIL

Audit Trail

| Month | Process |
|----------------|--|
| August 2008 | <ul style="list-style-type: none">• Secured IRB and PRMS approval from Virginia Commonwealth University and the Massey Cancer Center, respectively |
| September 2008 | <ul style="list-style-type: none">• Interviewed Lula and Lily• Transcribed interviews and wrote in reflexive journal• Reread transcripts, noted prominent themes, and modified questions |
| October 2008 | <ul style="list-style-type: none">• Interviewed Lucille, Susie, Molly, and Faith• Transcribed interviews and wrote in reflexive journal• Reread transcripts, noted prominent themes, and modified questions |
| November 2008 | <ul style="list-style-type: none">• Interviewed Jennifer, Susan, Jean, and Rebecca• Transcribed interviews and wrote in reflexive journal• Reread transcripts and began the process of line-by-line coding, arriving at a total of 111 initial codes |
| January 2009 | <ul style="list-style-type: none">• Reread transcripts and began the process of focused coding and memo-writing |
| February 2009 | <ul style="list-style-type: none">• Began further sorting and organizing codes into distinct categories and subcategories• Continued memo-writing and met with an auditor to discuss current categories and subcategories |
| March 2009 | <ul style="list-style-type: none">• Began member checking by sending a list of categories and questions to auditors; received auditor feedback and incorporated changes into categories and subcategories• Began the process of theoretical sampling by contacting participants for comments and feedback, and to address any gaps in the data• Began writing up the results and discussion sections of the manuscript |
| April 2009 | <ul style="list-style-type: none">• Continued calling participants who could not be reached initially; successfully reached a total of 3 participants• Continued revising categories and subcategories based on advisor feedback• Finalized manuscript |
| May 2009 | <ul style="list-style-type: none">• Presentation of data |

APPENDIX F
INTERVIEW QUESTIONS

Interview Questions

Interview 1

- How do you make sense of that? What do you think is going on?
- What was that like when the doctor said it was cancer? What was your life like after you were diagnosed?
- How has been working for you?
- What kinds of things help you get through when you get depressed? How do you deal with that? And that's been helpful for you?
- What does church help you with?
- Was the experience the second time around different? Did you feel different?
- How do you feel when you hear that?
- A lot of people say when they first hear the word 'cancer,' they think about, "Oh my gosh does this mean I'm going to die?" or "What does this mean?" I'm wondering if you can relate to that?
- Can you tell me more about that? What that experience is like?
- What do you mean when you say you're ready?
- What kinds of things get you into that mindset where you say to yourself, "I'm ready if God calls me"?
- Has the way you think about the world changed? Or your lifestyle?
- Can you describe that for me? Is there a way to describe that?
- What is that like knowing things fluctuate so much?
- Did you ever think about survival or your own mortality before you were diagnosed with cancer? Did that ever cross your mind?
- When you say live right, do right can you explain what that means to you? What that looks like?
- When you think about your mortality or death, what kinds of things do you think about?
- How do you feel when you think about those things, either leaving people behind or feeling no sickness?
- What would that do for you, helping other people?
- Did something happen right before you felt low or was it just all the physical symptoms?
- What do you mean different?
- How is it having a friend with you when you come to treatment?
- You said she was ready...how do you know? Do you think that's something you will know too? And what does that do for you, knowing that she's in a better place?
- Is there anything that I didn't ask that you wanted to add or feel like I should know that's important to your story?

Interview 2

- What were you first thoughts on hearing your cancer diagnosis?

- Can you tell me more? Like what kinds of things?
- So what happened from there?
- And how did you cope?
- So what was going through your mind, you know, when all these things were happening? What were you thinking?
- How did that help you?
- So what do you do with those thoughts when you think about facing your mortality here? What do you do?
- How do you make sense of that? What do you think is going on?
- You said you prepared yourself so you weren't quite as shocked. What did those steps look like? What was so difficult about it?
- What kind of thoughts and feelings do you have today when you sit and think about having cancer and going through it?
- What's normal for you?
- You talked briefly before about after being diagnosed you think about the possibility of your mortality and those things just come up. Are those thoughts that you had before?
- What did that mean to you? How did you deal with that? What were you thinking when that happened?
- You talked about how bad the surgery was for you and what was that like?
- How do you make sense of that now? What happened?
- So what kinds of thoughts did you have when you thought about how you might not possibly be here?
- As you sit here today do you have any thoughts about surviving?
- Is it something that you think about now? Your mortality?
- Anything you want to add or something that's important to your story?

Interview 3

- What were your first thoughts when you heard that you had cancer?
- A lot of people say when they first hear that they have cancer that they think about their own death or their mortality. I'm wondering if that fit with you in anyway or if it came later?
- And when you did finally get around to thinking about yourself, what was that? What was going on there?
- You said if you went downhill tomorrow and you had to accept it, what would accepting look like? What would that mean?
- Did you ever think about your own death before cancer or being diagnosed?
- When you think about it now, sitting here, do you have any reactions, thoughts or feelings about the possibility of dying?
- You said when you reach a certain age, like 60, you start thinking about it more. Why do you think that is?
- What do you mean as a problem? What makes you feel better about it?

- So being able to do those things and making the little changes, what is it? What is it mean to you? What does it do for you?
- And how do you usually cope with things?
- Do you think that influences the way you've handled having cancer and living with Beth [your daughter]?
- You mentioned having close friends and neighbors, what's that like having them nearby?
- Do you feel like your relationships have changes since you've been diagnosed?
- Your friendships or your relationship with your daughter. Do you think any of it has changed?
- Has life been really different for you since cancer?
- Did you want to finish your thought, was there anything else you wanted to add?
- So what made you feel useful?

Interview 4

- So what were your first thoughts on hearing your cancer diagnosis?
- What was your reaction? And what about the other times you were diagnosed?
- What do you think would've happened if you had time to wait?
- Some people say that when they first get diagnosed with cancer that the first thing they think about is, "Oh my gosh, I might die." And I'm wondering how that fits with you?
- What did that do for you, being able to do those things again?
- Can you explain to me, just what kinds of thoughts you had, feelings you had when you read the Internet article your friend gave you or you thought about the surgery, what was going on with you at that time?
- Can you tell me more about that? Like what kinds of things you felt like?
- What kinds of emotions would you use to describe what you were going through?
- Did you ever have thoughts about your death before you were diagnosed with cancer?
- What did that do for you? Getting your stuff in order?
- How did you manage the thoughts of about potentially dying? What did you do to cope with that?
- What do you think she went through? What did you see her go through?
- How different were you thoughts about death after you were diagnosed with cancer versus your family or your friends being diagnosed with cancer?
- So what is living for you?
- What kinds of things as Susie do you look forward to doing?
- What does that look like for you specifically?
- And what has life been like for you since cancer?
- So would you say life has changed considerably or are there things that you can think of that's just been significant changes?
- What do you notice? How can you tell it's working? Can you tell me how?
- So how did those things change your perceptions on life? Your outlook on life?

- So in what ways did your outlook on life change after those experiences?
- This is a new question that I haven't asked anyone yet. But I'm wondering how having a female only cancer, how—if that affected you in anyway?
- And as you sit here today, what do think about or what do you feel about having peritoneal cancer?
- I'm wondering do you have different ways of think about the cancer in order to help you manage it?
- And what do you like to do for fun? How do you enjoy life?
- How do you make sense of that?
- What do your friendships do for you during this time? Um, how do they make you feel? What do they provide for you? Do you feel differently about your friendship?
- What is it like being on people's prayer lists and being prayed for?
- Well is there anything you wanted to add that I didn't ask that you feel is important for me to know to add to your story?

Interview 5

- So what were your first thoughts when you heard that you were diagnosed with cancer?
- What did that progress?
- You said earlier that you had time to read up on things and read books and things like that and some people have said that having time just drove them crazy or made them even more anxious so I'm wondering how it was like for you to have that time?
- Some people say that the first thing that they think about after they've been diagnosed is their own death. And I wonder how that fits with you?
- What does that mean, ready? Can you talk more about that?
- What do you think will happen after you die?
- What about it do you think brings such peace?
- Did you think about this before having cancer? Is your death something you thought about before cancer too?
- What's the happy aspect of it?
- Would you say that having been diagnosed with cancer makes you think about this more or differently than before being diagnosed with cancer?
- When you sit here right now with me talking about this is there any particular thoughts or feelings you have?
- Would you mind explaining to me about that a little more?
- And how has your life changed for you since being diagnosed?
- What was the hardest part for you in the work transition?
- Do you feel like your relationships have changed too then?
- What was it like telling them?
- And your relationships with close friends or other family members, did you feel like that had changed since you had been diagnosed? And having them around and available, what does that do for you?

- What do you think living is for you? What does it mean to be alive, to live?
- Do you have an idea of what your purpose in life is or what your duties are? And how did you know that?
- Did you ever go through a stage where you thought, “I’m not lucky. This is really hard”?
- And if it’s not too personal for me to ask, what kinds of things do you pray for or pray about?
- As you sit here right now, do you have any particular thoughts on your cancer? Or any associated feelings?
- How would you sum up your life if you had to?
- What was your life for before you had children? What do you think about your children? When you think about your children is there something that you feel or think about immediately?
- I’m wondering if having ovarian cancer, which is specific only to women, I wonder if that made you feel a certain way or made you feel certain thoughts?
- Is there anything you want to add that you feel is important to your story that I just didn’t ask you?

Interview 6

- So what were your first thoughts on hearing your cancer diagnosis?
- What happened after that? After you realized that you did have cancer?
- How did the event unfold? What happened after that?
- What kind of thoughts?
- And what was that like to relearn everything? Relearn even the simplest things?
- Did you have any thoughts or feelings?
- How did you get through it? What kinds of things helped you?
- So what was like to be a nurse and also to be a patient at the same time because you have this medical background?
- I wanted to ask you because a lot of women say that when they’re first diagnosed they think, “Oh my gosh, you know, what if I don’t make it? Or what happens if treatment doesn’t work?” And I was wondering if you had any similar thoughts or if any thoughts like that ran through your head?
- You mentioned that you wrote an obituary after you found out you had cancer. And I haven’t heard that from other women before so I’m wondering sort of what made you feel like you wanted to do that and what did you write about?
- What do you feel like you have left to do?

Interview 7

- So what were you first thoughts on hearing that you had cancer? And then what happened from there?
- So did life change for you significantly would you say? In what way?
- Who did you feel like wasn’t there?

- So when you realized that—and your husband’s nodding in agreement with you with everything you’ve been saying—when you realized that what happened? How did you feel? How did you act?
- A lot of times when people say they were first been diagnosed with cancer that they think, “Oh my god, what if I die?” It’s the first thought that runs through their head and I’m wondering if that fits with you in anyway or affected the way that you changed your relationships?
- You talk about your faith a lot. Can you tell me about that? What it is in your life?
- Does that change your perceptions on things?
- And did the cancer play into becoming more aware of that?
- Do you feel like you’ve figured out what yours is?
- Those moments that you think about your death and the possibility of it, what are those moments like for you? How do you manage it?
- So what do your thoughts shift to?
- So what’s living? What is that?
- What was it about having cancer that really changed those relationships other than different things that have happened? What did you expect? So what did you feel, what were you thinking?

Interview 8

- What were your first thoughts on hearing your cancer diagnosis?
- What about when he first told you that you had cancer? What was your reaction?
- And what happened from that point?
- What was that experience like having a hysterectomy?
- Did you have any particular thoughts or feelings after your surgery or before?
- How has your life changed do you think since being diagnosed with cancer?
- What kinds of things was your mind on constantly?
- It sounds like you noticed physical changes? What was that like?
- A lot of women that I talk to said that they had to relearn how to do a lot of things and that there were a lot of things that they couldn’t do anymore because of having cancer. Do you find that to be true for you too?
- And what about your relationships with your family and friends? How is that?
- Can you tell me more about that?
- How so? How does it make a difference?
- What about people caring makes you feel good?
- A lot of people say that when they first hear the word cancer, that they think, “What if I don’t make it?” or “What if I die?” And I’m wondering how that fits with your experience?
- Did you ever think about your own death before having cancer?
- What do you believe? So how do you manage not knowing? If you had a timeline that it would make you more worried?
- So, what do you think—so what is living for you?

- Can you tell more about that and what you believe in?
- When you think about that right now sitting here, how does that make you feel?
- What do you think happens to you after you die?
- From the beginning or the middle—what has life been like for you since having cancer?
- So all those things that were important to you and you can't really do anymore, what is that like? How do you deal with it? Are there things that you do to make up for that? Do you feel like there have been major restrictions on your life? What is a way that you deal with it?
- And when you feel sad that you can't do those things, how do you manage those feelings?
- What other ways has life been like for you since cancer?
- Your relationships with your family and friends you said were great. Did you find that they changed after you were diagnosed?
- So what was that like for you knowing that those relationships stayed the same regardless of whether you had cancer? What about it makes you feel good?
- Do you feel like your life views have changed, the way you see the world? Can you describe it to me?
- Are there certain moments—you described one of them—are there certain moments where you do think about cancer more?
- So as you sit here today, do you have any thoughts about your survival and moving forward?
- And what are those things for you? Going on and moving on?
- And how do you cope? How do you see cancer? Anything else with that?
- And how do you make sense of you having cancer?

Interview 9

- What were your thoughts when you were first diagnosed with cancer? What were your first thoughts when the doctor told you?
- How did you get to the point where you weren't afraid of dying?
- How do you ready yourself?
- What does God do for you?
- What do you think happens to you after you die?
- How do you make sense of your cancer?
- What does that look like for you, dealing with it, being strong, what does that mean?
- And what does worrying mean?
- How do you know you're being strong?
- You said you've had moments where you felt depressed and down. What was going on during those moments?
- What do you live for? What keeps you going?
- What does that do for you, being able to do those things?

- So then how do you make sense of that? What do you think God intended you to get out of this?
- Do you think you know now why you have cancer? How does it make you feel not knowing?
- Have your relationships changed at all since you've had cancer with your family and friends?

Interview 10

- So what were your first thoughts on hearing your cancer diagnosis?
- What was it like hearing that you had to have a full hysterectomy?
- What was it like hearing that?
- And your husband mentioned before he left that you two both went through a very long process in restructuring and reframing a lot of things about your life. And so I was wondering if you could tell me about that?
- And what would be some of those negative things?
- A lot of women say that part of the process is when they get a cancer diagnosis they think, "What if I don't make it? What if I die?" And I was wondering how that fits with you?
- Did you feel like your life changed in some significant way after cancer?
- What do you think was the motivation for those—for that change? What was it about cancer?
- And you talked about being so healthy and living in a healthy way so how do you make sense of getting cancer?
- And you also talked about relationships and do you feel like they've changed and if so how?
- What does that do for you to have that type of support?
- And your husband and close family, what about your relationships with them?
- So as you sit here today, what kinds of thoughts or feelings do you have about having cancer or about the cancer experience?
- Is there any point in your experience with cancer where it wasn't good?
- Do you know what the reason is or how you make sense of it?
- What is living for you?
- What is it like to have someone who is going through something similar to you?
- Is there anything I didn't ask that you feel is important for me to know for your story?

Vita

HaNa Kim was born and raised in St. Petersburg, Florida. She received her Bachelor's degree from the University of Florida in 2004. In the same year, HaNa accepted a position in the counseling psychology program at Virginia Commonwealth University, a program known for its richness in health psychology research. Her research interests are broadly within health psychology, with specific emphases on women's health and psycho-oncology. Recently, she accepted a pre-doctoral internship position at the Memphis Veterans Affairs Medical Center in Memphis, Tennessee, where she will complete the final requirement for her Ph.D. Upon graduation in May 2010, HaNa aspires to embark on a career as a health psychologist at a large teaching hospital conducting psychological evaluations, teaching, mentoring, and engaging in multidisciplinary research.