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### Living Past Your Expiration Date: A Phenomenological Study of Living with Stage IV Cancer Longer than Expected

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LIVING PAST YOUR EXPIRATION DATE: A PHENOMENOLOGICAL STUDY OF  
LIVING WITH STAGE IV CANCER LONGER THAN EXPECTED

A Dissertation

Presented to the Faculty of  
Antioch University Seattle  
Seattle, WA

In Partial Fulfillment  
of the Requirements of the Degree  
Doctor of Psychology

By  
Cynthia (Cyndi) TC Levine

June 2008

LIVING PAST YOUR EXPIRATION DATE: A PHENOMENOLOGICAL STUDY OF  
LIVING WITH STAGE IV CANCER LONGER THAN EXPECTED

This dissertation, by Cynthia (Cyndi) TC Levine, has  
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who recommend that it be accepted by the faculty of the  
Antioch University Seattle at Seattle, WA  
in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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## ABSTRACT

### LIVING PAST YOUR EXPIRATION DATE: A PHENOMENOLOGICAL STUDY OF LIVING WITH STAGE IV CANCER LONGER THAN EXPECTED

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More treatment options exist today for persons diagnosed with terminal cancer extending lives longer than expected, though there is little known about the psychosocial needs or resources for these individuals. This study describes the experience of living past the expiration date and still living with Stage IV cancer. A transcendental phenomenological approach was used to elucidate vivid expressions of this experience in a sample population of five Caucasian women. The women survived beyond their prognoses of an earlier expiration, are not close to imminent death, and are still living with incurable breast cancer metastases. The aim of this phenomenological inquiry is to illuminate the themes and essences of this phenomenon in hopes of expanding comprehension of the challenges this growing population confronts.

Data was collected through individual open-ended, unstructured in-depth interviews. At a second meeting, each woman, having been asked to find or create an expressive representation of their experience, verbally described their creations in an unstructured dialogue. All interviews were audio recorded and transcribed verbatim. Through the methodological processes of bracketing, phenomenological reduction, imaginative variation,

and synthesis, the themes and essences that surfaced revolved around the constancy of change and duality. Five core themes emerged from the data: awareness of mortality; interaction with medical systems and treatment; living on a roller coaster; feeling different from others; cancer invades and changes how you live. All of the themes are interrelated and together capture the complexity of the lived experience. Living with dying, longer than expected is an experience that profoundly impacts every aspect of these women's lives. It catapults them into a new paradigm where they have to renegotiate life daily. Each woman's lived experience is both unique and shares collective threads. The essences that emerge from the combined strands are a continuum of hidden suffering and the varying dimensions of fortitude that are experienced while living in a liminal time and space between life and death. Facing mortality all the women accept the challenge to live fully and maintain hope; but in their vulnerability few are able to sustain the feeling that the good times outweigh the terrible times.

The electronic version of this dissertation is at OhioLink ETD Center, [www.ohiolink.edu/etd](http://www.ohiolink.edu/etd)."

## DEDICATION

This work is dedicated to the memory of the women who taught me the meaning of “Make Today Count” and in honor of the women who live with cancer metastases. You grace my life with your honesty, humor, and struggle. I would also like to dedicate this endeavor to my father, Selwyn (Babe) Charapp, whose memory I hold dear.

## ACKNOWLEDGMENTS

I am deeply grateful to the five women co-researchers who enthusiastically and generously shared their time and their lives with me. I am appreciative of their willingness to help me understand the full range of their thoughts and feelings and allow me to know their intimate sorrows and joys.

I thank my dear husband, Alan, whose encouragement was readily available throughout this entire commitment with no complaints. I completed this dissertation only because of his enduring love and support that kept me from perishing physically and mentally. I am indebted to my children, Casee and Kyle for their technical assistance. I am grateful to my children and to my son Jesse for their patience when I needed to set this project as a priority over spending time with them. I am forever thankful for my mother, Harriet Charapp, for all the conversations, humor and love that bolstered my spirit and nudged me gently to completion.

Researching this project was challenging and rewarding. I am especially grateful to my committee chairperson, Mary Wieneke, Ph.D., for her scholarly guidance, incredible patience and encouragement on this most daunting endeavor. I extend many thanks to my committee member Ned Farley, Ph.D. for introducing me to phenomenology, opening my mind to existentialism, and embracing the I-Thou relationship. I am thankful for the keen curiosity of my committee member, Judith Gordon, Ph.D., who generously gave of her time and offered her professional knowledge and skills to this process.



I extend appreciation to my cherished friend Adela Basayne, MA., and to my brilliant colleague Tatiana Shepel for their critical thinking and feedback, for helping me brainstorm ideas, and for dialogues full of empathy and belly laughs. I am grateful to my colleague, Diane Harris, LCSW, for her wisdom and exceptional compassion in doing the work we love.

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## Introduction

### *Overview*

There is much unknown about the causes of cancer and the numerous aspects that influence the manifestation and course of the disease remain unidentified. Statistics grimly show that cancer is the second leading cause of death in the United States. In 2007, it is estimated that 1,444,920 million new cancers, not including carcinomas in situ (cancers that are noninvasive), will be diagnosed and that 564,830 Americans can expect to die of cancer (National Cancer Institute (NCI), 2005, American Cancer Society (ACS), 2005-2006). If current world wide trends continue, as in the year 2000 where 8 million persons were diagnosed and one in seven died of the disease (World Bank, 2003), the World Health Organization (WHO) predicts that in 2020, more than 84 million new cases of cancer will be diagnosed yearly (2006). These statistics and the indeterminacy of origins and unknown trajectory often trigger intense fear and the general perception that any stage or type of cancer will be a death sentence.

In the last ten years, the overall five-year survival rate from all cancer has increased 65% resulting from earlier diagnosis and from new and improved treatments (ACS, 2005-2006). This percentage though does not distinguish between cancer types or cancer sites or indicate those cancers that are decreasing in incidence and those that are increasing in prevalence. This percentage also excludes the distinction between those who are cured, those who continue to receive treatment, and those who have had a recurrence. In one type of cancer, in the instance

of women with advanced breast cancer, it is estimated that at least 150,000 women are currently living with advanced metastatic breast cancer (NCI, 2005). Research indicates that individuals experience different levels of social and psychological distress depending upon the primary cancer site and severity; those with advanced cancer are at greater risk for severe psychological distress (Dropkin, 2001; Edleman & Kidman, 2000; Hammerlid, Ahlner-Elmqvist, Bjordal, Bjorkland, Evensen, Boysen, et al., 1999; Pascoe, Edelman, Kidman, 2000; & Dropkin, 2001; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). For cancers diagnosed in the early stages, most health care professionals and patients impacted by cancer agree that it can be controlled and that there is a high probability for cure. Unfortunately, for persons diagnosed with advanced, late stage cancer their prognosis is less promising and imminent death is often expected by the patient, their friends, family, and medical staff. Cancer patients after hearing from their doctor that they will not recover from their disease and perhaps being told to “go home and get your affairs in order,” begin preparing to die. Yet, there are patients who do not die, who outlive their prognosis. Of those who outlive their expected death some now have no evidence of disease (NED), while others persevere with Stage IV cancer, living longer with dying and managing the disease through the combination of aggressive treatment to combat the cancer and palliative care to enhance their quality of life.

In the past, treatment options for persons with metastatic cancer were limited to surgery, chemotherapy, and/or radiation until that treatment eventually failed, and then they were administered end of life care which was available with varying degrees of quality. In the last 10 years, numerous quantitative and qualitative studies addressing end of life physical, psychosocial, spiritual, educational concerns, and death and dying awareness have been



instrumental in improving the comprehensiveness and quality of care in the final stages of life (Brietbart, 2001; Coyle, 2006; Kissane, 2002; Little & Sayres, 2004; Ryan, 2005). With newer targeted-cell treatment options, the advent of clinical trials, and revised, expanded palliative care guidelines, persons with cancer metastases are living for an extended time and with a modicum of comfort. Metastatic cancer no longer inevitably brings an immediate death sentence. Medical prognosis is not always accurate and does not define every individual's course of illness (Vigano, Dorgan, Buckingham, Bruera, & Suarez-Almazor, 2000). However, metastasized cancer currently continues to denote *incurable* disease and necessitates having to live with ongoing treatment procedures, with intermittent periods of remission and relapse, comfort and suffering, hope and fear, grief and joy, and the constancy of uncertainty. This is especially poignant for those who have survived the prognosis of their demise.

When we got the scans back...they said it must be helping him...we said no, no, no, don't get your hopes up too much...it was a huge adjustment in every way because we had been living as if we only had tomorrow, if that. We had gone on a trip to Italy. We had done things that we couldn't possibly afford doing in the long run. So it was a major shift to suddenly have to think long term. At the same time, all of life sort of comes flooding back in, all of life's everyday worries...we were elated for about two days, and then we thought, Oh God, What are we going to do now? (Knuti, Wharton, R., Wharton, K., Chabner, Lynch & Penson, 2003, p.115)

This study will explore through individual life experiences the phenomena of living past one's expiration and enduring with Stage IV cancer. (The terms metastatic, terminal, advanced cancer, and Stage IV cancer are used interchangeably in this study) Phenomena in this study are defined as the way things appear to a person in experience or consciousness. Phenomena are plural, and phenomenon is singular. Phenomenological implies "having to do with the experience" (Fischer, 2006, p. 436).

My interest in this topic arose from my work in co-facilitating an ongoing weekly support group for women with metastatic disease. All of the women have been diagnosed with Stage IV cancer. Their self-named group, “Making Today Count” is an open group in which new members can enter the group at anytime; the group has almost tripled in size since its inception in February 2005 with 20 women in attendance. Sixteen members have passed away since the group’s beginning, ten of those women died within the last nine months. Yet the census of the group has remained unchanged. The health of members is varied as are the amorphous size of the group and the mood of the participants from week to week. On any given week, there will be 10 to 20 members asking each other for resources, assistance with problem solving and decision-making, and seeking social and emotional support. They cherish the opportunity to bond with each other, paradoxically connecting while speaking of their isolation. They discuss treatments, lab reports revealing both good and bad news, express their concerns and dreams, their hope and joy, their fears, anger, frustration and despair. They share how cancer impacts their lives, their intrapersonal reflections, and responses from interpersonal relationships, and they endeavor to make meaning of their experience. I have been profoundly impacted by each of their personhood, their willingness to be candid with some of life’s most difficult and complex circumstances, and their cumulative tribulations and jublations.

The group’s beginning was forged from the failure of other support groups to address the needs of women diagnosed with terminal cancer. Advanced cancer patients have different concerns than individuals with early stage cancer (Baker, Denniston, Smith, & West, 2005; Carter, MacLeod, Brander & McPherson, 2004; Davies & Sque, 2002; McIlmurray, Thomas, Francis, Morris, Soothill & Al-Hamad, 2001; Rainbird, Perkins & Sanson-Fisher, 2005; Turton

& Cooke, 2000; Wong, Franssen, Szumacher, Connolly, Evans, Page, et al., 2002; Living Beyond Breast Cancer, 2005). Individuals who are living longer with metastatic cancer face different issues than either the newly diagnosed or those closer to end of their life. Yet, there is scant research or public attention addressing this population. There are even fewer professional services and/or formal support groups. “Making Today Count” is the only support group for women with a terminal diagnosis and is the only group for any persons with Stage IV cancer within a 100-mile radius.

Most of the public spotlight focuses on education, screening, early detection and treatment of early stage, curable primary tumors. While foundations are dedicated to cancer research and there is a swell of charitable fundraising and celebratory events that recognize and address survivors and their issues when treatment ends and remission endures, people with advanced cancer feel invisible. People with cancer metastases are not publicly represented or are often misrepresented. The women in the metastatic group feel others avoid them and they desperately want to be acknowledged.

“We are what others want to forget because we are painful reminders of what can happen.” “I am people’s worst nightmare.” “We are only recognized as losing the battle.” “I can heal myself and live or I can heal myself and die.” “The two strongest emotions I have from my cancer experience are fear and alienation... Lot’s of people are afraid and don’t know what to say to me and I feel like I do not fit in...People I expected to support me either denied I was ill or only saw me as a disease.” “We want to be seen and heard...for both our struggle and aliveness... and known for more than our disease.” “We want to educate the rest of the world that CANCER IS NOT A DEATH SENTENCE.” (Group members, 2006-2007)

Within this group, a constellation of women speak often about their experience of having lived one to several years past their expected demise:

I survived past my expiration date... If I was a carton of milk, they would have thrown me out by now... People have said goodbye to me three times now... it's amazing that I made it this far... I'm still alive and working, but my husband wants to know where I'd like to travel next before the next round hits... I might die in six weeks, six months, or six years from now... The neuropathy in my hands and feet from the treatment is keeping from walking and knitting, two of the things in life that keep me sane. I'm going to take a break from treatment for three months because treatment should never interfere with life... Everything changes and you go through an intense emotional state, then things settle down to a new normal and you adjust, and then BOOM, something else comes up in the scan and you get wheeled around all over again... There are NO ROLE MODELS FOR HOW TO DO THIS. (Group member, 2007)

This small gathering of women is growing in numbers. It is likely that there are others outside the group also searching for understanding and answers as to how to go beyond surviving to thriving, living longer than others before them who had terminal cancer and how to cope while struggling with the impact of advanced cancer, knowing they are going to die sooner than later. They search for how to hold life and death simultaneously and to decipher, now that they are not dead, how to live.

They speak of disfigurement, and missing body parts, unrelenting fatigue, chemo brain, disabling neuropathy, lymphedema, and other side effects of treatment and disease. There are huge issues around body image and self-esteem, and struggling to overcome the feeling that their bodies had betrayed them. There is also a sense that society, and our culture have also betrayed them... they'd been 'sold a bill of goods'... especially around stress, workaholism, materialism, and the development of a "false self." Many agreed cancer, like other types of human suffering, is a "great equalizer," one that strips you down to your core, and leaves you naked... no hair, missing body parts, and loss of the "self" you thought you were. With this however, is the opportunity to rebuild a more honest, authentic self. With all crises, is the opportunity to change, to grow, to even transform... to know, without hesitation, what is really important (Harris, 2007).

Thriving beyond surviving is the optimal word when living more authentically. Results from a multiple case study in Sweden describe three women with terminal cancer able to alter their life perspective, transforming their view of illness into a less limited paradigm and

achieve greater authenticity and a more meaningful life (Armandt & Rehnsfeldt, 2002). This finding is further qualified by other studies that explored cancer patients' experience of hope and finding meaning (Benzein, Norberg & Saveman, 2001; Elliot & Olver, 2006; Winterling, Wasteson, Sidenvall, B., Sindenvall, E., Glimelius, Sjoden, et al., 2005). The numbers of articles that are concerned with cancer patients' problems outweigh the few studies about how advanced cancer patients can embrace life.

Metastatic cancer inevitably alters every aspect of a person's life. Advanced cancer affects the whole person- physical, psychosocial, sexual, and spiritual- as well as their family members and their communities. The impact of cancer between people differs broadly: some live with a good quality of life, while others live in distress, and it is most likely that many live along the continuum. Research encouraging the unfolding of first person accounts of living beyond the expected time of death and living with metastatic cancer is needed to articulate adequately the "essences" of this phenomenon. Essence is defined here as the "intrinsic or indispensable properties that serve to characterize or identify something" (Webster Dictionary, 2008). Studying the rich descriptions and meanings that individuals with Stage IV cancer ascribe to their experiences of unexpectedly living longer while dying gives the participants an opportunity to have their voices heard and may help metastatic cancer become more graspable and less unspeakable.

### *Purpose of the Study*

The purpose of this study is to explore the lived experience of having outlived one's expected time of death *and* currently living with terminal, Stage IV cancer. After reviewing the

literature, talking with professional cancer care providers, and listening to individuals in a weekly group for women with metastatic disease, it has become clear that little is understood about the lived experience of this particular phenomenon. The aim of this phenomenological inquiry is to illuminate the essences of surviving cancer beyond an expiration date and living with terminal, incurable illness. Through in-depth interviews and symbolic expressions rich, thick, detailed descriptions of individuals' thoughts, feelings, ideas, situations, and responses will be elucidated. Reflecting upon the complexities and nuances with an attitude of discovery and a sense of awe, we may come to know how individuals find meaning in their living and dying in relation to this phenomenon. This inquiry does not seek causes or explain why this phenomenon exists, rather it seeks to gain a broader understanding of the phenomenon through the eyes of humans living the experience.

The benefits of this study to the participants includes having their stories commemorated, expressing unique and common facets of their human experience in this particular situation, engaging in the process of meaning making, and advocating for greater understanding of their illness through shared knowledge.

### *Research Question*

The following research questions serve as a guide to this phenomenological study: "What is the experience of living past one's expiration date and living with Stage IV cancer?" "What is the meaning of this experience?" The 'what' connotes curiosity on the part of the researcher and denotes that knowledge about this phenomenon is lacking. "Experience" refers to the

descriptions one seeks to present in vivid and accurate terms, in complete terms, what appears in consciousness and in direct seeing- images, impressions, verbal pictures, features of heaviness, lightness; sweetness, saltiness, bitterness, sourness; openness, constrictedness; coldness, warmth; roughness, smoothness; sense qualities of sound, touch, sight, and taste; and aesthetic properties. (Moustakas, 1994, p.59)

The use of the word meaning seeks to understand the individual's way of making sense of and coming to know their experience.

## Literature Review

### *Introduction*

Empirical literature on living *past* expected time *and* living *with* one's cancer metastases is scarce. One source to describe the experience of outliving one's prognosis was found in the HIV/AIDS literature. Siemens' (2000) work with HIV/AIDS patients describes living past expiration as a "double confrontation" (p. 75). Siemens states that first the patient receives a diagnosis and then he/she finds out that treatment can alter prognosis and prolong life. People are frightened by having to change their sense of identity into that of a person who may continue to live after preparing to die. After one had already accepted inevitable death and had withdrawn from daily life events- quit jobs, sold houses, said good-bye to family and friends- the process was in reverse. The problem became not coping with death but coping with life and the crossroad of living with dying (p.74-77). In an extensive search of empirical cancer literature, only a paragraph or two within a few studies alluded to living beyond one's expiration date and living longer with terminal cancer.

There is a plethora of research on the quality of life in early stages of cancer, predominantly in the area of breast cancer. Twenty-five percent of breast cancer patients have metastases, yet Goodwin (2003), in reviewing random controlled trials (RCT) that addressed psychological distress, found 30 articles in which only six focused on advanced cancer. Health related quality of life (HRQOL) research is abundant for persons in early stage cancers, though is quite limited in studies for Stage IV cancer; out of 189 studies treating 31,510 patients, only 9% of advanced cancer patients were involved in any assessments (Bottomley & Therasse, 2002). Despite the prevalence of cancer recurrence, newly diagnosed advanced cancers, and



deaths from cancer, the prospect for psychosocial research appears dim as current funding initiatives are focused primarily on cancer survivors who are not currently dealing with ongoing disease (Anderson, Shapiro, Farrar, Crespin, & Wells-DiGregorio, 2005).

A diagnosis of Stage IV cancer creates a rupture in how one negotiates the world, and when one is neither a survivor nor at death's door, the constant ambivalence of embracing life or preparing to die may be massive and confusing. It is a bizarre roller coaster of hoping for a cure, knowing miracles are rare, and facing death amidst the recurrence, destruction, diminution/stabilization, and recovery trajectory experienced repeatedly. Once considered a sprint, a quick death, living with Stage IV cancer is now viewed as a marathon with the finish line not yet in full view, and as with any long road race, endurance depends upon familiarization with all the different phases. The study of those with advanced cancer is complex and multidimensional. Cancer metastasis affects not just the body; it intrudes upon and alters every aspect of a person's life, which includes the physical, psychological, social, cultural, and spiritual domains (De Faye, Wilson, Chater, Viola, & Hall, 2006). To understand all of the various facets within these domains and the whole person who is living with metastases and who has lived past her expiration date, the literature review will cover extant research that relates to prognostic features, to the identification of needs, and explores both the distress and resilient aspects that accompany an advanced cancer diagnosis.

### *Biology*

Cancer is more than one disease; it is 200 plus different diseases resulting from uncontrolled abnormal cell growth (Veach, Nicholas, & Barton, 2002). Early cancer development is defined as healthy cells that grow and divide without control or order; this

abnormal growth in a particular layer of rapidly dividing cells that destroys healthy tissue is labeled a malignant tumor (ACS, 2006). Metastases occur when the abnormal growth of these cells increases and proliferates beyond the confines of one area, cancer cells break off and travel through the bloodstream or lymph system to distant parts of the body (Eyre, Lange, & Morris, 2001). National Cancer Institute (NCI) (2006) declares that cancer can occur at any age, anywhere within a person's body, and grow slow or extremely fast with some cancers easy to detect, while others are insidious. Across persons, the same cancer can manifest differently as can the potential for total remission of abnormal cells resulting in cure, tumor growth, or metastases. Significant differences exist across cultures and cultural minorities and underserved populations are at greater risk of developing and of dying from cancer due to diminished access to preventive screening, lack of health insurance, inadequate care, and/or patient skepticism in specialized oncology treatment (ACS, 2004; Brennan, 2004; McGinnis, Williams-Russo, & Knickerman, 2002; Moore & Spiegel, 2004).

Not all causes of cancer are known, nor is the course of growth understood fully. Some factors that influence the development of cancer are external (e.g. tobacco, environmental chemicals, radiation and infectious agents) and others are internal (e.g. age, gender, inherited mutations, hormones, and metabolic mutations). These can act together to initiate a sequence that promotes abnormal growth (ACS, 2006). The most common occurring types of cancer are lung, breast, colon, and prostate (NCI, 2003). Melanoma, ovarian, head and neck cancers, and lymphomas in young adults are increasing. One in every two men and one in every three women are at risk for developing cancer in their lifetime (Veach, Nicholas, & Barton, 2002).

Cancer can be cured, become chronic, or lead to death (Holland, 2000). The severity of cancer depends upon the type (origin/primary site), tumor size, and whether it has metastasized to other parts of the body. Some malignant cells are so abnormal that their tissue of origin cannot be determined (Ellerhorst-Ryan, 2002). Increasing cancer severity is scaled from Stage I to Stage IV. Cancer that has metastasized is labeled Stage IV cancer and deemed incurable, though some types of cancer can be controlled for a longer length of time with various treatments and under certain conditions that are dependent upon patient variables and the specific cancer characteristics. Although they live with fragility, with the threat of bones breaking easily, women who have breast cancer metastases to the bones can live a longer time if there is a response to treatment and the spread of cancer cells does not reach other organs (Turner, Zapart, Pederson, Rankin, Luxford, & Fletcher, 2005). When uncontrolled cancer growth invades essential organs in the body, causing them to cease functioning, death ensues (Eyre, et al., 2001). Lengthening the time cancer can be controlled, to extend life, is the goal of treating advanced cancers, but predicting how long one will survive is difficult.

### *Prognostication*

Receiving a diagnosis of terminal cancer (advanced, metastatic, considered incurable) generally means one can expect 2 years or less of life; life expectancy is the longest for metastases from breast cancer and the shortest for lung and colon cancer (Jermal, Murray, Ward, Samuels, Tiwari, Ghafoor, et al., 2002). Vast diversity and yet similarities exist with in advanced cancers. There are multiple factors in the manifestation of any particular cancer, and a myriad of treatments are used to control advanced cancer in combination with a heterogeneous group of cancer patients, all with varying characteristics, values, and contextual

factors, making prognostication for exact length of survival and time of death very difficult (Addington-Hall, MacDonald, & Anderson, 1990; Heyse-Moore & Bell, 1987; Parkes, C., 1972). A Canadian meta-review of literature from 1996-2000 uncovered 31 articles in which 12 studies investigated clinicians' predictions and 19 studies focused on prognostic factors (Chow, Harth, Hruby, Finkelstein, Wu, & Danjoux, 2001). Prognostic accuracy compared actual survival time to what was predicted. General predictions for plus/minus one year in one out of twelve instances were inaccurate: 12% overestimated survival time and 9% underestimated time of death in an optimistic direction. Most studies were able to predict with more accuracy imminent death within one month or less time. In a study with 210 patients, there was less than 54% accuracy for predictions greater than six months, and for predictions at the two to six month interval, there was 68% inaccuracy (Vigano, Dorgan, Buckingham, Bruera, & Suarez-Almazor, 1999). A second study by Vigano and colleagues (2000), did a systematic review of 7,089 patients who at the time of the study lived 1-11 weeks before dying. They examined 139 different variables as possible predictors of survival and established that there were at least 18 prognostic factors. The researchers concluded that cancer death in patients is from multiple causes, that common predictors for events are not always apparent, and few studies provide information on patient characteristics or use any standard criteria to define the 'terminal phase.' Patients themselves with a terminal illness may dismiss the severity of their illness because of the number of times one perceives the doctor to be wrong in their prognosis (Davies & Sque, 2002). Weeks, Cook, O'Day, Peterson, Wenger, Reding, et al. (1998) found that 80% of patients rated their chances of living for six or more months longer than their doctors' estimates.

Predicting survival and disclosing prediction to patients with advanced cancer disease is amongst the most difficult tasks that physicians face (Markowitz, 2003; Chow, et al., 2001). Previously, the tendency was to withhold a terminal diagnosis from the patient as doctors thought it detrimental to a patient's frame of mind (Christakis, 1999). The work of Glasser & Struss (1965), Kubler-Ross (1995), Saunders (1983), and Young & Cullen (1996) posited that patients benefit from knowing of their mortality. This knowledge assists people to engage in the necessary tasks for completing a life while still living. Doctors are concerned with how much information to give patients, worry about giving the wrong prognosis, and believe that disclosing prognostic uncertainty will increase a patient's anxiety, reduce trust in the doctor-patient relationship, and destroy hope (Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Christakis, 2000). Gordon and Daughtery (2003) in a 90-minute focus group examined 14 oncologists' attitudes towards disclosing distressing information to patients. Even though they felt pressured by their patients, these doctors chose not to disclose and their reluctance to convey information was evidenced through their responses. Responding in metaphors, the language doctors used to describe disclosure was depicted in terms of violence ("assault, hammer them, beat people over the head, force prognosis down their throats"), indicating the level of harm they believed they would cause their patients (p.155). Other researchers believe that expressing prognostic ambiguity carefully could engender hope and a decrease in the patient's anxiety associated with ignorance and uncertainty (Christakis, 2000). The rationale underlying this approach is that disclosure is believed to increase self-determination and cause less emotional distress in reference to making decisions about treatment and management of the death process (Gordon & Daughtery, 2003).

Additional research focuses on what and how to disclose information to patients, rather than whether to disclose or not (Parker, Baile, de Moor, Lenzi, Kudelka, & Cohen, 2001). Eighty-nine percent of 1,032 UK patients with advanced cancer wanted as much information as possible, either good or bad (Fallowfield, Jenkins, & Beveridge, 2002). Evans, Back, and Arnold (2006) found that cancer patients want information that informs them of their doctor's technical expertise and his/her understanding of their disease in order to make treatment decisions. Reviewing several studies, these researchers indicate that 95% of patients want information about treatment options, side effects, and symptoms, 85% want to know the longest expected survival time with treatment, 80% want to know their five-year survival rate, and 80% want to discuss their family and social concerns with their doctors (Evans, Back, & Arnold, 2006).

In another study, one hundred and twenty-six patients with metastases (56% male) completed a 35-item survey using a Likert scale to rate their preferences for content and format of what they found most helpful in discussions with doctors (Hagerty, Butow, Lobb, & Pendelbury, et al., 2005). This research indicated that those who had lived longer with cancer and those with longer expected survival time wanted more realism. The participants expressed preferences for diagnostic information in reference to timing and manner of presentation. Younger patients, with higher needs and high expectations of medical care, were more anxious and placed greater emphasis on emotional support for themselves and their families from doctors or other resources. Older adults rated expert opinion and empathetic approaches as more helpful and desired emotional support directly from their doctors versus other formal organized support. The most commonly endorsed item for all participants was information pertaining to their ability to enjoy quality of life even if expectancy is uncertain. Ninety-eight

percent of respondents wanted doctors to be more realistic, appear to know about their cancer, provide an opportunity to ask questions, insure pain control, and acknowledge them as individuals when discussing prognosis (Evans, Back, & Arnold, 2006). Patients with a terminal diagnosis want to know that their doctors understand their needs and care about them (Evans, Back, & Arnold, 2006). Patients reported their desire to be known and to be regarded with dignity and worth by their providers (Davies & Sque, 2002). Establishing meaningful connection meant that the provider made eye contact, sat down rather than stood, remembered the patient's name and case details, did not rush consultations, and informed the patient and their family members about all aspects of their disease (Thorne, Kuo, Armstrong, McPherson, Harris, & Hislop, 2005).

### *Treatment*

Treatments to control cancer are complex and varied and interact differently within individuals (Eyre, et al., 2001). At a time when a person is most vulnerable, treatment decisions require the patient to learn a new language and master the vocabulary quickly in order to ask intelligent questions, find appropriate resources, and make optimal treatment decisions (Holland & Lewis, 2000). Medical treatment decisions for Stage IV cancers may involve surgically removing tumors, and preventing spread or recurrence through chemotherapy, radiotherapy, immunotherapy, and/or hormonal therapy (Chang, Ganz, Hayes, Kinsella, Pass, Schiller, et al., 2006). Controlling cancer requires aggressive treatments with toxic drugs that may cause severe side effects. When metastases are not responding well to conventional treatment, patients can participate in experimental approaches such as clinical trials, procedures in which new drug therapies are tested in humans (Varricchio, Pierce, Walker, & Ades, 1997).

There are many obstacles to participating in clinical trials, such as meeting acceptability criteria, the availability of a trial in a person's geographic area, accessibility to the location of the trial, and ability to follow treatment protocols (McCabe, in Varricchio, et al., 1997). Participating in clinical trials is chosen in the face of living with the reality of incurable disease while hoping for a miracle cure; participating is experienced as the "need to try anything and everything" and offers the individual a sense of "giving to others" through medical science (Moore, 2000, p. 742).

Deciding and administering treatment depends upon a non-exhaustive list of factors that consider patient and disease characteristics, previous treatment responses, as well as the details of when and how to administer the various drugs or radiation protocols (Ellerhorst-Ryan, 2002; Holland & Lewis, 2000). Treatment requires constant doctor appointments and involves tumor marker blood tests and numerous body scans (positron emission tomography (PET), computed tomography (CT), bone, and /or functional magnetic resonance imaging (fMRI) to assess cancer activity (Chang, et al., 2006).

The physical side effects of these treatments and effects from the cancer itself may include changes in bodily functions and changes in appearance. Specific physical side effects, numerous, sometimes unpredictable, and often debilitating, may result in one or more of the following such as: insomnia (Ancoli-Israel, Moore, Brundrage, et al., 2001; Holland & Lewis, 2000), appetite changes (Hopkinson & Corner, 2006), hair loss, nausea, anorexia, cardiac toxicity, neuropathy in hands and feet, fatigue, pain, changes in vision or hearing, short-term memory loss, dental problems, sexual dysfunction, loss of fertility, edema, and loss of mobility, all of which for Stage IV cancers may be cumulative and can be intermittent or unrelenting (Brennan, 2004; Chang, et al., 2006; Holland, 1998). From 480 UK outpatients receiving



palliative care, diagnosed with eight different types of cancer, 90% reported 26 current symptoms on a 29-symptom checklist, with a mean of 10 symptoms for each patient (Lidstone, Butters, Seed, et al., 2003). Fatigue, the most prevalent and most distressing side effect reported by three quarters of advanced cancer patients, has been under investigated, not been successfully treated, and is often overlooked in discussions between doctors and patients (Lidstone, et al., 2003; Mock, 2001; Potter, 2004). Pain is reported by 65-85% of patients with a terminal diagnosis (Yates, Edwards, Nash, Walsh, Fentiman, Skerman, et al., 2002). Across cultures, health care surveys reveal that there are barriers to pain management in reference to the economics of not having insurance, or insurance not reimbursing for treatment, restrictive regulation and unavailability of controlled substances, inability of language to describe pain, lack of visibility, and invalid measurement tools (Anderson, et al., 2002; Gunnarsdottir, 2002; Morrison, 2000). Significant differences exist across cultures in which cultural minorities and underserved populations are at greater risk of developing and of dying from cancer (ACS, 2004 & Moore & Spiegel, 2004). There are also patient barriers such as a reluctance to report pain, reluctance to follow treatment directions fearing addiction, and fear about drug effects on disease progression (Anderson, et al., 2002; Gunnarsdottir, 2002; Morrison, 2000).

New technology to detect and new treatments to control cancer continue to be developed, yet there is still no cure for Stage IV cancer. There are no longer standards or a best option for recommending specific treatments for advanced cancers (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006). Blank and colleagues, in a large study of medical experts and cancer patients, describe the overwhelming nature of uncertainty of the cancer situation, outdated knowledge about outcomes, and the complexity of making treatment choices. The struggle to heal or find comfort is often carried beyond the traditional medical establishment.

Complimentary and Alternative Medicine (CAM) or integrative health care is increasingly utilized by persons with advanced cancer to restore physical, emotional, and spiritual balance (Mulkins & Voerhoef, 2004).

### *Complimentary and Alternative Medicine*

CAM focuses on health rather than sickness and emphasizes patient participation and therapeutic encounters through a variety of methods. A handful of research articles address spontaneous remission resulting from the changes in individual's psychological perspective and/or nutrition (Achterberg, Mathews-Simonton, & Simonton, 1977; Berlund, 1995; Hildenbrand, Hildenbrand, Bradford, & Cavinet, 1995; Hirshberg, & Barasch, 1995). The Institute for Noetic Sciences (IONS) (2000) documented over 1,000 cases of spontaneous remissions with no evidence of disease and is currently investigating 67 cases of persons who have lived 20 years beyond their terminal prognosis.

The National Center for Complimentary and Alternative Medicine (NCCAM) classify treatment into five categories (Lev-ari, Maimon, & Yaal-Hahoshen, 2006, NCCAM, 2006). The first is alternative medical systems that are built on complete systems of theory and practice such as homeopathy, naturopathy, and Chinese medicine. The second category includes mind-body interventions designed to enhance the mind's capacity to affect bodily functions. Techniques used are meditation, prayer, mental healing, guided imagery and relaxation (Rossman, 2002), expressive arts therapies such as visual and/or textural art (Collie, Bottorff, Long, & Conati, 2006; Puig, Lee, Goodwin, & Sherrard, 2006; Reynolds, 2003 & Reynolds & Prior, 2006), music (Aldridge, 1998; Daykin, Bunt, & McClean, 2006; Hartley, 2001), drama (Gray, Sinding, Ivanoffski, et al., 2000; Sinding, Gray, Fitch, & Greenberg, 2002),

storytelling (Pelus & Krebs, 2005), poetry (Furman, 2006), dance/movement (Bullington, Nordemar, R., Nordemar, K., Sjo, & Flanagan, 2003; Dibbell-Hope, 2000), and videography and photography. Third, there are biologically based methods that might include supplements found in nature such as herbs, foods, and vitamins. In the fourth category are manipulative and body-based methods such as chiropractic, osteopathic, and massage. The last category involves energy therapies that are intended to affect energy fields that are within and surrounding humans. Examples of these techniques are Qi Gong, Reiki, acupuncture, and Therapeutic Touch. Several studies report that CAM addresses physical and psycho-social-spiritual needs of cancer patients that biomedicine cannot, which are evidenced in reduced pain (Gatchell & Turk, 1999), less psychological distress, decrease in social isolation, increase in communication skills and enhanced interpersonal interactions, enhanced spiritual well-being and general, overall, improvement in quality of life (Hana, 1995; Kissane, 2000; Puig, et al., 2006; Reynolds & Prior, 2006; Vickers, Straus, Fearon, & Cassileth, 2004). Even though 66-80% of persons with terminal cancer report using some type of CAM (Bernstein & Grasso, 2001; Jones & Demark-Wahenfried, 2006; Shen, Andersen, & Albert, 2002), most do not use CAM as a replacement for conventional medicine. One study reports that 43% do not tell their doctors that they are using CAM, perceiving their doctors as disinterested and/or dismissive of the benefits (Balneaves, Kristjanson & Tataryn, 1999). Gamin (1999), Graham-Pole (2000), Rossman (2002) believe that physicians, nurses, and clinicians are beginning to recognize the role CAM programs play in the healing process as some cancer centers now have well-arts programs on-site (Puig, et al., 2006). The appeal of CAM to a wide variety of cultures is great due to varied beliefs systems and customs (Struthers & Eschiti, 2004).

Humor is one category not mentioned by NCCAM. Humor, a surprising feeling to emerge in oncology, is acknowledged as a mature defense mechanism, yet psycho-oncology literature on humor is sparse (Joshua, Cotroneo, & Clarke, 2005). Two studies mention humor as a positive coping strategy used by women with metastatic cancer (Bowes & Butler, 2002; Kissane, Grabsch, Clarke, Christie, Clifton, Gold, et al., 2004). On the internet, there are seven cancer joke sites, and some patients have created web sites that advocate using humor for coping. A few books have emerged on the topic recommending ways to enjoy and find joy in life in the threat of death (Joshua, Cotroneo & Clark, 2005; Klein, 1998; Richards, 2002).

### *Psychological Factors*

Cancer affects every domain of a person's life. The consequences of changes to body appearance resulting from lost body parts due to surgery, from physical symptoms directly related to the cancer and/or side effects from treatment often lead to psychological distress. Psychological distress is defined as a "unique discomforting emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporarily, or permanent, to the person. The nature of the experience may be psychological (cognitive, behavioral, emotion), social, and/or spiritual" (Ridner, 2004, p.537).

Psychological distress can arise also from financial and legal matters related to living with cancer (Folkman & Greer, 2000). As cancer progresses the financial burden becomes a major concern. The costs of cancer are in excess of \$209 billion per year, with more than 20% of Americans having inadequate or no medical insurance coverage (ACS, 2006). In a survey of 1, 020 people with cancer, 35% of respondents incurred \$10,000 of debt, 24% incurred ten to twenty four thousand dollars of debt, 15% incurred twenty five to forty

thousand dollars of debt, and 12% of respondents had to turn down treatment options because they could not afford them. Thirty-two percent of respondents lost their jobs or were demoted at work and 34% felt trapped into staying in their jobs for insurance benefits (Lance Armstrong Foundation, 2004).

Terminal cancer is not limited to the patient; it impacts the whole family. Literature on the psychological impact of a terminal cancer on a family posits that managing the uncertainty of the disease, balancing the burdens of caretaking with other responsibilities, adjusting to changes in family roles, and increased social isolation all cause distress in all family members (Andreassen, Randers, Nasland, Stockland, & Mattiasson, 2005; Baider, Cooper, & De-Nour, 2000; Edwards & Clarke, 2004; Veatch, Nicholas, & Barton, 2002). Family distress in turn creates additional anguish for the patient.

Psychological distress from a terminal diagnosis can result in sadness, grief, adjustment disorders, and major depression that undermine a sense of pleasure, diminish ability to connect with others, take away a sense of meaning, and have an overall negative effect on quality of life (Holland & Lewis, 1998; Kelly, McClement, & Chochinov, 2006; MacGuire, 2000). Research reveals depression is more prevalent in those who have advanced cancer than in the general public (Kissane, Grabasch, Love, et al., 2004). Depression is estimated to affect 50% of cancer patients (Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). Other symptoms of distress could include fear (of uncertainty, of developing treatment side effects, of treatment's ineffectiveness, of pain, of being a burden, of not being in control) which results in anxiety in 30-60% of persons with advanced cancer, and can develop further into an anxiety disorder (Ferrell, Smith, Cullinane, & Melancon, 2002; Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005). Women living with advanced

breast cancer have expressed that their lives feel like a *time bomb* waiting to explode (Davies & Sque, 2002). In one study, recurrent cancer reportedly caused psychological distress with intrusive thoughts and avoidance (Anderson, et al., 2005). These researchers reported that this distress was not necessarily accompanied by global distress or quality of life disruption. The authors concluded that this evidence, “at least initially” supports a learning theory concept in that the habituation to hearing a cancer diagnosis may be responsible for distress. (p.1544). Other researchers demonstrated that as malignancies worsened the number of physical and psychological symptoms increased in prevalence and in severity causing additional distress (Kadan-Lottick, et al., 2005; Lindstone, et al., 2003; Ryan, Schofield, Cockburn, Butow, Tattersal, Turner et al., 2005). Researchers caution that symptoms are not static and must not be explored in isolation through one-time questionnaires, but with regards to the social context in which they occur on a continual basis (Anderson, et al., 2005; Brennan, 2004).

Distress is significantly under-diagnosed and under-treated (Murillo & Holland, 2004). Oncologists often do not recognize or recommend treatment for psychological distress and patients report difficulties in communication with their doctors (Turner, et al., 2004). Physicians’ detection of stress was lowest among those patients with the highest self-rated disease (Merckaert, Libert, Delvaux, & Razavi, 2005). In an online survey from the Lance Armstrong Foundation (LAF, 2004), 1,020 self-selected persons with cancer reported that 70% dealt with depression; 49% had needs other than medical and only 30% said that their doctors were willing to discuss those needs with them; and 53% said that the practical and emotional aspects of cancer were harder than medical issues. Analyzed tape recorded conversations between doctors and 251 patients with advanced cancer indicated that patients

spend 145 of their utterances talking about psychosocial issues to their doctors while the doctors devoted only 3% of that time to these verbalizations (Kadan-Lottick, et al., 2005).

The process of learning to live with an illness is social and directly affected by culture and the input of attitudes of others (Brennan, 2004). Patients perceive clinicians as promoting optimism, a fighting spirit and being positive, which in turn caused them to conceal their emotional distress (Byrne, Ellershaw, Holcombe, & Salmon, 2002). Forcing a patient to accept the concept of positive thinking limits patients from grieving, setting goals, or planning appropriately for the future they do have left (Rittenberg, 1995). Holland & Lewis (2000) label this the *tyranny of positive thinking* and remind readers that patients' feelings of optimism and fear of cancer change hourly. Persons with terminal cancer are praised for looking well and for their courage, but they are rarely praised for how well they express their fear, grief, and anger. Patients want to be seen and heard, for their doctors to say "yes we see your pain and accept your fear" (Frank, 1991, p. 65). Sontag (1978) wrote early on that fear of the many unknown aspects of cancer perpetuate blaming the victim, placing responsibility for creating the disease and for getting well, or not, within the individual. Self-help literature and some research studies conclude that positive feelings lead to cure and recovery, while negative feelings or certain personality characteristics may cause disease and can influence its course (Cousins, 1979; Classen, Koopman, Angell, & Spiegel, 1996; Miller, Manne, Taylor, Keates, & Dougherty, 1996; Simonton, 1992). Much controversy surrounds this issue in the empirical literature. Several studies claim the existence of a cancer-prone character type, personality "Type C" (one who suppresses negative emotions, is unassertive, compliant with external authorities, and acts helpless and/or exhibits hopelessness) and that this personality type is associated with causation and significantly affects cancer remission and recurrence (Bleiker, van der Ploeg,

Hendricks, & Alser, 1996; Everson, Goldberg, Kaplan, et al., 1996; Grossarth-Maticek, Bastiaans, & Kanazir, 1985; Hahn & Petitti, 1988). Conversely, Nakaya, Tsubono, Hosokawa, Nishino, Onkubo, Hozawa, et al., (2003) and Zalonik (1994) reported no evidence to conclude that either stress reduction or positive mental attitude *alone* could alter the biological course of cancer significantly. Petticrew, Bell, and Hunter (2002) did a meta analysis of 26 studies focused on comparing a “fighting spirit,” a positive coping style, to negative coping characterized as a hopeless/helpless attitude. They found that there was little sound or consistent evidence to generalize that psychological coping style played an important part in survival from or recurrence of cancer. There is concurrence in empirical research that psychological distress does result from advanced cancer, though disagreement is prevalent among studies that correlate degrees of psychological stress with specific coping strategies (Zabalegui, 1999). De Faye, et al., (2006) conclude from their in-depth, semi-structured study of 52 advanced cancer patients, found that stress is a complex, multidimensional experience in which there is not any particular pattern of coping best for relieving psychological distress. They suggest that different cancer related stressors require different means of coping.

All of the research on supportive expressive group therapy (SEGT) interventions for persons with a terminal illness concur that this type of intervention leads to improved psychological outcomes, specifically, reduced depressive symptoms, ameliorated feelings of hopelessness, increased coping efficacy, improved social functioning, and served to demystify death (Beachman, McDermott, O'Brien, & Turner, 2005; Cameron, Booth, Schlatter, et al., 2007; Edmonds, et al., 1999; Goodwin, 2005; Kissane, et al., 2007; Kissane et al., 2004; Llewlyn & Murray, 1999). However, none evidenced that SEGTProlonged survival as did an earlier study conducted by Spiegel (1989).



The difficulty in comparing these studies lies in the definition of advanced cancer. Some studies include Stages II and III, others look at patients who have discontinued any aggressive treatment, and all use different definitions and measures to assess psychological distress. Longitudinal studies were rare and the length of time that relief from distress, remission, or survival prevailed was not evaluated.

### *Psychosocial factors*

Persons with terminal cancer experience multiple intrinsic and extrinsic losses. They lose a basic trust in their body's physical functioning and how they used to appear (Armstrong-Coster, 2004). They lose independence and a sense of coherence (Brennan, 2004) and continuity with their past in terms of daily activities, involvement in work and social pursuits (Brennan, 2004; Carter, 2004). Bury (1982) describes this loss in terms of how illness is a 'biographical disruption' because it impacts not only on a biological level but also affects how individuals perceive their entire life trajectory. The disruption poses a threat to the individual's self-recognition and self-affirmation, where beliefs and strategies for coping may no longer work. Carter (2004) and Davies & Sque's (2004) qualitative research endeavors with women with breast cancer metastases describe this encounter as having "to reconcile a new me" to deal with what is no longer the life they used to live and to accept a 'new normal.' The women also experienced a sense of social isolation and a feeling that they differ from others, as if they were on the "outside looking in" (Davies & Sque, 2004, p.589). Potter's (2004) research utilized a hermeneutic approach to investigate the effects of fatigue among six persons, 45 to 75 year olds, with cancer metastases. Results from their study indicated that few coping strategies proved effective and fatigue affected every other aspect of the person's life. Patients

experienced frustration at isolation caused by the unpredictability of changes in energy and the necessity to make limited social plans. Patients felt a sense of loss of normalcy and had difficulty with accepting their situation and struggled against changing their expectations.

Armstrong-Coster (2004) investigated the experiences of five respondents, living and dying of cancer, ages 35 to 76 years, noted that interviewees over time changed in response to their experiences with cancer and their ongoing disease led to changes within their social relationships. In order to maintain life during the crisis points of illness, surrendering social obligations was necessary (p.124). Armstrong-Coster made note of the challenges to her research by describing those few who did not conform to their anticipated trajectory, either by dying prematurely or by outliving their prognosis. Though living past expiration was not explored in depth, the one respondent who outlived her prognosis two times before dying, who was 48 years old and a mother of two children, experienced less fear of death, though increased alienation. She was seen by others as recovering, but during these periods, her own progress was in marked contrast to her physical appearance, which called on her to keep up appearances, even as she felt despair. All the respondents on the living and dying trajectory struggled with changes in self and in relationships. Interviewees had to surrender social connections “as others just could not appreciate the scale of their fears or the reality of the danger they faced. This resulted in anxiety being repressed and when it inevitably leaked out, it provoked and threatened relationships that had once been close” (p. 126). In the midst of intense uncertainty accompanied by the threat of death, there is the loss of identity, loss of relationships, loss of a sense of order, loss of original plans and rearranged plans, and the loss of a long tomorrow (Boland, 1993; Mitchell, 2006). Lost also are the illusions of control and security (Ferrell, Smith, Cullinane, & Melancon, 2002).

Armstrong-Coster's (2004) study provided evidence that the disclosure of terminal diagnosis led to the experience of profound shock and existential crises. Other studies, in a query for living with metastases/advanced/terminal disease, primarily investigated existential emergency (the urgency when survival is threatened by extinction) at the time of imminent death. The majority of cancer research in this area covers care preferences in the one's final days (Yedidia, & MacGregor, 2001), the anticipation and preparation for death (Mystakidou, Tsilika, Parpa, Katsouda, Galanos, & Valhos, 2005), therapy with the dying (Cohen, & Block, 2004), the desire to hasten death (Blindman & Cherny, 2005; Hudson, Kristjanson, Ashby, Kelly, Schofield, Hudson, et al., 2006), dying with dignity (Goldsteen, Houtepen, Proot, Abu-Saad, Spreeuwenberg, & Widdershoven, 2006), and the lived experience of dying (Clayton, Butow, Arnold, & Tattersall, 2005; Ryan, 2005). Coyle (2003, 2004, & 2006) did a series of interpretive phenomenological studies about the experience of dying from cancer during the last six months of life with participants who had expressed a desire to hasten death at least once. Coyle (2004) interviewed seven patients (four male, three women) with diverse types of advanced cancer, who all experienced severe physical pain in their final months. They describe their experience with opioid use to reduce pain as both a blessing in temporary relief and a guarantee of a peaceful death, and as a burden because of their struggle with self, with religious beliefs, and with a readiness to die. In struggling to maintain life, the fear of pain was greater than death. In a subsequent study, the hard work and urgency of preparing to die soon involved an additional seven patients who were receiving only palliative services. Coyle (2006) interviewed four males and three women (90% of the sample was Caucasian) one to six times over six months with a focus on their attitudes towards life and death. The predominant theme was how hard it was to prepare to die. The tasks of dying, for which there were no role

models, was hard work in terms of negotiating relationships: relationship to the health care system, to changing sense of self, to pain or other distressing symptoms, and to the existential crisis of imminent death. Coyle refers to this time as the ‘existential slap.’ In their desire to maintain dignity and sense of worth while living, the participants engaged in searching for and creating a system of support, orienting themselves to the disease and maintaining control, and struggling to find meaning and create a legacy.

### *Psycho-spiritual factors*

This stress of cancer is compounded in Stage IV as persons must also deal with the threat to their survival (Goodwin, 2003). Distress and despair that accompany a terminal cancer diagnosis is described as an existential or spiritual crisis (Hirai, 2003; Kelly, McClement, & Chochinov, 2006). Existential/spiritual distress is “defined as an individual confronting her/his own mortality arising from feelings of powerlessness, disappointment, futility, meaninglessness, remorse, death anxiety, and disruption with his/her engagement with and purpose in life” (Kissane, 2000; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006, p. 291). Research consistently shows that over 70% of those living with terminal cancer desire spiritual issues to be considered as part of their care (Anandarajah & Hight, 2001; Luoma & Blomqvist, 2004; Wong, Franssen, Szumacher, Connolly, Evans, Page, et al., 2002). Spiritual coping encompasses existential well-being, the finding of meaning and purpose in one’s life, striving for authenticity and arriving at a sense of peace with a positive perspective, and/or includes faith, a belief in and connection with a higher transcendent power or spirit, though not necessarily through organized religion (Breitbart, 2001; Lin & Bauer-Wu, 2003; Paloutzian & Ellison, 1982). Several studies have shown that spiritual well-being positively correlates with

subjective well-being, reducing anxiety and depression and significantly improving self-esteem, self-efficacy, and quality of life with level of comfort (Bowes, Tamlyn, & Butler, 2002; Giese-Davis, Koopman, Butler, Classen, Cordova, Fobair et al., 2002; Greenstein & Breitbart, 2000; Greisinger, 1997; Griffiths, C., Norton, L., Wagstaff, J., & Brunas-Wagstaff, 2002; Laubmeier, K., Zakowski, S., & Bair, J., 2004; Lee, et al., 2006; Lewis, 1989; Lin et al., 2003; McCoubrie & Davies, 2006; Morita, Tsunoda, Inoue, & Chihara, 2000; White, 2004; Yang & Yin, 1999).

Gotay, Issacs, and Pagano (2004) addressed the ‘exceptional survivor’ in their study: 160 persons who had a prognosis of a 25% life expectancy of five years or longer, were all living well with a high quality of life five years post diagnosis. This exceptional survivor group was matched with a control group for age, gender, ethnicity, marital status, and year of diagnosis, though they differed in cancer types and treatment variables. The exceptional survivor group had mostly stomach and lung cancers, the control group had cancers with much better prognoses and were predominantly breast and prostate cancer patients. The exceptional group received treatments that were more aggressive than the control group in which surgery was likely the only treatment. Conducted in Hawaii, all of the study participants had Asian or Pacific Islander ancestry. Rather than focusing on what explained living for an extended time, “the primary goal of the study was to describe the well-being and its correlates in long-term survivors who had exceeded their life expectancies,” (p.882). The research design incorporated predictive indicators, psychological, and quality of life measures. The researchers found that for a disease in which the risk factors are not highly predictable and in which persons have little control over the outcome, the participants’ well-being had little to do with

thinking positively or optimism, and more to do with finding meaning and resilience in a negative situation (p.888).

If distress is an unavoidable cancer experience, hope is central (Ferrell, Smith, Cullinaene, & Melancon, 2002). Hope with cancer is broad in context. Hope is described in various categories in the lives of those with terminal illness (Clayton, Butow, Arnold, & Tattersall, 2005; Moore, 2001). Hope is defined as “a belief that the present situation can be modified and that there is a way out of the difficulties” and is interconnected with one’s quality of life (Rustoen, 1995, p.356). Hope is seen as a nonlinear reconciliation with life and death (Benzein, Norberg & Saveman, 2001). For those living with terminal cancer, hope as a noun refers to a cure or a need to fight the disease. Hope as a verb is hoping to live longer than expected, taking each day as it comes, exploring realistic goals, hoping to heal relationships and enjoy special times with family and friends, to find meaning in life, and hoping for a peaceful death (Clayton, et al., 2005; Eliot & Olver, 2007; Maliski, Sarna, Evangelista, & Padilla, 2003).

Hope for women with breast cancer metastases means continuing life despite ongoing treatment (Ferrell, Smith, Juarez, Melancon, 2002). Despite suffering and loss, women in the face of death with cancer have transformed their desolation into consolation (Mitchell, 2006; Ohlen & Holm, 2006). Carter (2003), from interviews with ten participants, emphasized that themes emerging from living with advanced breast cancer were experienced on a continuum and could not be seen as separate, rather they were interconnected. As patients experienced difficulty in one part of their life, other areas were also likely to be affected. From a grounded theory approach, Carter theorized that the central overarching theme was about ‘taking charge.’ Taking charge was about acceptance and adaptation, a sense of autonomy, and a sense of moving on (p. 611-618). The challenge was not in dying; rather it became how to

live, and how to live in the face of death. The polarization of life and death, hope and fear creates new awareness and wisdom which in turn fosters the opportunity for growth whereby women with metastatic cancer have, through introspection, acquired positive meaning and made certain resolutions, accepted greater responsibility for their own authenticity, and found life more beautiful and valuable (Arman & Rehnsfeldt, 2002, p.292-295).

### *Palliative Care*

All of the aforementioned research has been the impetus for the development of guidelines for palliative care. People with Stage IV cancer can receive palliative care if requested. In the past palliative care was administered only to those who were no longer receiving any type of treatment aimed at cure or control of cancer metastases. There are international efforts to establish clinical practice guidelines to improve the quality of psychosocial care for patients with cancer that hope to promote effective evidenced-based treatments and reduce ineffective and harmful interventions (Turner, et al., 2005). The formation of these guidelines is the result of empirical literature that assessed patients' needs. Palliative care, once confined to providing comfort for the dying, has broadened to include the physical, social, psychological, and spiritual aspect of coping with cancer over the entire continuum of cancer care and is administered simultaneously with disease modifying (curative or controlling) care (Kuebler, Lynn, & Rohen, 2005). Psychological distress in palliative care is currently described by the National Comprehensive Cancer Network (NCCN) as the continuum of distress that can extend from feelings of vulnerability, sadness, and fear, to depression, generalized anxiety, panic, feeling isolated or spiritual crisis (2007, p.6). NCCN has

developed guidelines to address each facet of distress (Kelly, et al, 2006, p.780). NCCN

(2006) defines palliative care as follows:

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care to persons with life-threatening or debilitating illness. Palliative care is patient and family-centered care that focuses upon effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and culture(s). The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families regardless of the stage of the disease or the need for other therapies. Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care. (p.5)

### *Summary*

As of January 2002, approximately 10.1 million persons were living following a diagnosis of cancer in the United States (ACS, 2006). Some of these people are cancer free with *no evidence of disease* (NED) while others are still undergoing treatment and/or symptom management (Palliative Care). The number of persons living with a terminal diagnosis is increasing with the advent of new treatments. Many persons living with cancer metastases vacillate between being distressed and cautiously optimistic. The research on extended survival while living with metastatic cancer is in its infancy and literature on the experience of outliving one's prognosis is meager. Research over the last 35 years clearly indicates that living with a terminal cancer diagnosis impacts every aspect of one's life. The physical aspects of cancer and conventional cancer treatment can be severe and debilitating. Utilization of complimentary and alternative medicine is on the rise. The constant uncertainty that accompanies a Stage IV diagnosis challenges the individual to negotiate the tasks of living and dying simultaneously. Both quantitative and qualitative approaches suggest that psycho-social- spiritual concerns abound, yet support for patients' highest needs remain unmet (Schofield, et al., 2004). Patients



needs change over the trajectory of the illness, as do their emotions, yet throughout, terminally ill patients consistently report that obtaining information and support is critical, and that the process of sharing that information is as important as the content (Kirk, Kirk, & Kristjanson, 2004). Psycho-social-spiritual needs are framed by distress from unrelieved physical symptoms, intrinsic and extrinsic loss, social isolation, financial costs of treatment, concerns for family members, and a need to find meaning in the experience (Arnada, Schofield, Weih, Yates, Milne, Faulkner, et al., 2005; Coreil & Behal, 1999, Cossitch, Schofield, & MacLachlan 2004; Foot & Sanson-Fisher, 1995; Goodwin, 2003; Johnson, 1982; Kissane, et al, 2006; Sheard & Maguire, 1996; Wong, 2002). Palliative guidelines for clinicians have been recently expanded to address the concerns of terminally ill cancer patients and their family members based on evidence for best approaches. There are major limitations to the research. The methodology of studies uses different measures and variables to investigate similar issues that accompany a terminal diagnosis and definitions of advanced cancer and how terminal is defined vary between studies. The majority of studies have been conducted with predominantly well-educated middle income Caucasians, with a focus primarily on women with metastatic breast cancer. Much of the research is devoted to end of life care and the tasks of dying and very little focuses on life and living longer with well-being in terminal cancer. Prognostication is limited by the multiple factors that determine the progression or remission of disease and doctors' reluctance to disclose. In a literature search, no research has yet focused on the lived experience of outliving one's expected demise and living with Stage IV cancer. This study hopes to add to the current literature.

## Methods

### *Research Design*

The nature and topic of the research question is the guiding principle in choosing methodology. The research question “what it is like to live past one’s expected time of death and live with terminal cancer,” starts the inquiry with a desire for deeper awareness. This type of research strives to explore what is the lived experience and what is the meaning of this experience as discovered through first hand, personal accounts of the phenomena and understood through the language and expressive representation of the experiencing person.

Inquiry into the nature of a person’s experience with phenomena guides the researcher towards qualitative inquiries. Creswell (1998) contends that qualitative research is conducted based on the following premises: when the research question being asked is *what* as contrasted to asking *why*, *how many*, or *how frequently*, when the topic chosen is understudied, and when the topic would best be explored through ‘thick description’ in the participant’s natural setting. Thick description in this context refers to depth and not necessarily to volume. Qualitative research is a naturalistic inquiry that studies real world situations as they unfold. Qualitative research is chosen over quantitative methods when the research question is seeking discovery versus verification, relies on the description of participants’ subjective meanings of experience versus observable, objective measurement and explanation, and uses language or expressive representation versus numbers and charts to present data and findings. Qualitative research encompasses the holistic nature of a topic and contemplates all the parts equally, their interdependencies, and dynamics, versus quantitative research that searches for linear cause and effect with a few variables. Qualitative methodology acknowledges phenomena and listens

to its multiple voices. Participants' lived experiences of phenomena are not accessible through quantitative methods that name, manipulate, and measure only parts of a phenomenon (Fischer, 2006).

### *Phenomenological Approach*

Phenomenology dwells with and openly respects persons' own points of view and honors the multiperspectivity found in the life-world. Phenomenology is a low-hovering, in-dwelling, meditative philosophy that glories in the concreteness of person-world relations and accords lived experience, with all its indeterminacy and ambiguity, primacy over the known. (Wertz, 2005, p.175)

Phenomenology, a form of qualitative research, is the descriptive or interpretive study of how individuals experience a phenomenon in the everyday world. Phenomena could be from one perspective or from multiple perspectives, about actions, events, changes and/or appearances. Phenomenological descriptions could derive from the data of a single or a few individuals, from texts, literature, visual or expressive arts, and/or science. In situating phenomena in real life contexts, human experience can be explored in greater breath and profundity. It is an approach that "seeks to reveal more fully the essences and meanings of human experience" and "illuminate" that experience "through careful, comprehensive descriptions, vivid, and accurate renderings of the experience" (Moustakas, 1994, p. 105). The aim of phenomenological research is to gain access to the life-worlds of participants, which is their world of experience, and through their subjective, unique descriptions of the phenomena, discovers the structures, the meanings, and the common and uncommon nature of the lived experience. Amongst phenomenologists, many different schools of thought and approaches exist: interpretive, hermeneutic, reflective/transcendental, heuristic, existential, sociological,

dialogical, empirical, and psychological. Some of these terms reflect more than one form of phenomenology. Some researchers explain their approach not by the school of thought, but by naming a theorist whose specific techniques they are borrowing (Thorne, 2000). Doing phenomenological research begins then with understanding the philosophical origins of phenomenology and a statement about which form of phenomenological inquiry is to be utilized by the researcher.

Two very different schools of philosophy guide phenomenological methodology. Phenomenology's philosophical roots can be traced to the thoughts of Husserl (1859-1938), considered to be the founder of phenomenology, and Heidegger (1889-1976) in Germany (Bryne, 2001; Pollio, Henley & Thompson, 1997; Moustakas, 1994; Ryan, 2003). Both schools of philosophy are interested in the individual's lived experience, in the world of person's lived experience, the *Lebenswelt*. The dimensions of Lebenswelt are encompassed in the experience of four life-worlds, the *corporeal* (lived body- embodiment), *temporal* (lived time- time in which we live), *spatial* (lived space- environment), and *relationality* (lived human relations- relations with others) (Valle, 1998 & Yates, 2003).

Followers of Heidegger's philosophy conduct phenomenological research with a hermeneutic approach and are intent on interpreting the meanings that persons hold and form about the world (Shank, 2000). In Heidegger's approach, the researcher's role is "to give considerable thought to their own experience and to explicitly claim the ways in which their position or experience relates to the issues being researched" (Lavery, 2003, p.17).

Husserl's philosophy begins with the phenomenon itself. Followers of this school conduct empirical research focusing on participants' descriptions of their lived experience of the phenomenon and the meaning of that lived experience. The three main tenets of Husserl's

phenomenology incorporate the concepts of intentionality, Epoche, and intersubjectivity (Giorgi, 1985; Moustakas, 1994; Valle, 1998; Valle & Halling, 1989; Wertz, 1995; Yates, 2003). Intentionality, the basis of transcendental phenomenology, posits that an object, whether real or imaginary, is real to the person, the subject, who perceives it to be true. The individual's perception then is the primary source of knowledge and varies according to each individual's subjective experience. Intersubjectivity, through the sharing and relating of each subjective experience, is the manner in which others come to know the commonalities of the phenomenon. The role of the researcher then is to come to know the individual's lived experience by transcending her presuppositions through the process of 'bracketing' or Epoche, in order to see the world as it really is (Shank, 2000; Valle, 1998).

### *Epoche*

"Bracketing is a mathematical metaphor (that) involves putting one's natural attitude to the world 'in brackets' in order to place it temporarily out of the question" (Priest, 2000, p.61). "Epoche is a Greek word meaning to refrain from judgment, to abstain from or stay away from the everyday, ordinary way of perceiving things" (Moustakas, 1994, p.33). It involves setting aside one's theories, scientific assumptions, biases, and prejudices to accept the phenomena for what and how it appears. This process of suspending presuppositions about the world is the conduit to genuine discoveries, to find the meaning in the experience, the essences. Viktor Frankl (1973) says that finding meaning requires a certain attitude towards the world; the phenomenological attitude is "an openness of mind free of personal interest... an attitude directed at the essence of a situation that allows one to be reached or even captured by the situation" (p.62). The role of the researcher is then to remain as open as possible to the

‘other’ by putting to the side her own and the cultural understandings of the world. Being more attentively tuned to each participant’s way of seeing the world and to connect with the other’s consciousness the researcher, describes the phenomena precisely how it is heard and lived (Giorgi, 1985; Moustakas, 1994; Valle, 1998).

For Husserl, bracketing enabled the researcher to move towards understanding the essential structures of the phenomena that could then be brought together in a synthesis (Moustakas, 1994). Husserl purported that for one to see things “as they really are” requires a process of reflection, intuitive seeing, and free or imaginative variation (Giorgi, 1985; Moustakas, 1995; Wertz, 2005). Imaginative variation is the process of considering multiple perspectives and reflectively looking at the description of a person’s lived world to come upon elements (invariant structures/possible meanings) of the phenomena that would not otherwise exist (Garko, 1999; Giorgi, 1985; Fischer, 2006; Moustakas, 1994; Van Manen, 1997; Wertz, 2005).

Based on understanding the primary philosophy and the nature of the research inquiry, the methodology selected needs to include an appropriate, well-delineated set of procedures, and be justifiable. Letting the research question of what is the lived experience of living past one’s expiration date and living with Stage IV cancer serve as a guide, I chose Husserl’s transcendental philosophical existential perspective. The set of guidelines that was most appropriate and offered a credible and systematic process that allows for minor adaptations was Moustakas’s revised Van Kaam procedures, the transcendental phenomenological method (Moustakas, 1994). The methodology moves from collecting data from in-depth interviews or “self-dialogues, stories, poems, artwork, journals, and diaries, and other personal documents that depict the experience” with a few individuals in a natural setting

to focus on the unique textural and structural portrayals of the lived experience (Moustakas, 1994, p.18-19). From descriptive portals, the data in this study underwent a systematic analysis to arrive at a synthesis of the essences and meanings of the group of co-researchers as a whole. The presentation of this process brings the experience alive to capture the complexity, nuances, and essentials of the phenomena in the body of the manuscript.

### *Role of the Researcher*

The researcher's role is always directed towards the experiencing person, and therefore participants are often referred to as the *co-researcher* in phenomenological literature (Hubers, Graf & Lantinga, 2003; Moustakas, 1994; Valle & Halling, 1989). Co-researcher is a term that describes the subjectivity of the data producers, the participants in the study being interviewed. Their descriptions and the intersubjectivity of the researcher direct the data analysis.

The tasks of the researcher included screening and collecting data through in-depth interviews and subsequent expressive representations. These tasks included recruiting and screening participants/co-researchers. Methods of recruitment involved gaining access to participants by contacting local oncology service providers and posting recruitment announcements at cancer clinics and agencies that offer services to cancer patients. Another method of recruitment included what is known as "snowballing." This was a recruitment technique where one participant was asked to recommend others and where phone calls were made to gatekeepers of oncology services asking for recommendations of those who might be interested to contact the researcher. An open invitation was extended to any interested individual. Inclusion criteria was used to screen potential participants for appropriate fit to the

study. An informed consent sheet was distributed to interested individuals containing the researcher's name, title of the study, the theme of the research, and requirements, including the estimated time investment, of the research endeavor and that there would be no monetary compensation. Initial screening occurred by telephone or through a brief face-to face encounter. (see Appendix C) Potential co-researchers were screened for appropriateness for the study, their willingness to participate, if they had the time for individual interview meetings, and had the ability to articulate and express sensitive personal material. The researcher, a licensed mental health provider and nationally certified expressive arts therapist had the knowledge of networking and recruitment, twenty years of clinical experience and familiarity with screening measures, and interpersonal skills needed to build rapport and create an atmosphere of safety and compassion to encourage honest and comprehensive responses in exploring persons' lived experience. Specifically, the researcher followed the phenomenological researchers' guidelines established by Giorgi (1985), Moustakas (1994) and Wertz (1985). This researcher needed to maintain a non-judgmental, empathic presence, patience to dwell with the individual's description to become more sensitive to every nuance of the participant's self-presentation and the details of the description as they became magnified. The researcher practiced staying fully attuned to the psychological experience being described. The researcher attempted to remain open to the co-researcher's perceptions rather than attach her own meanings and/or preconceived theories and taken-for-granted beliefs to lived experience of the phenomenon. The researcher collected data, maintained proper storage of data, comprehensively analyzed data, reported findings, and drew summaries guided by the tenets of the phenomenological approach and adhered to professional ethical codes of conduct and State laws and codes.



### *Ethical Considerations*

An approved Human Subjects application was filed with the Institutional Review Board at Antioch University Seattle. Each participant received an oral review of the written information and informed consent form as outlined in Appendix A.

Confidentiality of participants was strictly enforced with pseudonyms applied to the raw data in transcription. Any mention of others persons by name in the participants' raw data description was disguised. Participants' verbal transcriptions and the primary researcher's written description of the individual co-researcher were made available to the participant for review, verification, and/or modification.

### *Data Storage*

Proper data storage was maintained. In addition to an electronic file of each co-researcher's transcription and written reports, a 'hard copy' file was created for each co-researcher. This file was labeled with the assigned pseudonym and color code. Each file contains the following documentation: the informed consent, the original audio/video recordings, hard copies of NVivo documents/reports, original textual description given to co-researcher for their verification or additions, any notes or communications between the participant and the researcher. Electronic information was backed-up onto a flash drive and stored with password security and kept with the hard copy files in a fireproof, secured storage container. The destruction of audio/video taping materials will occur as agreed upon with the co-researchers.

*Sample Population*

Empirical phenomenology research dictates the type of participants to include. The nature of the research requires individuals to describe their lived experiences with the phenomenon. Phenomenological inquiry requires deep engagement with a small number of participants. As potential participants were the primary source of data, a purposeful sample was utilized to elicit information rich descriptions to provide useful examples of the phenomena under study. Identifying persons who had related experience to the phenomenon was crucial. A brief pre-interview meeting took place by phone to screen potential participants for appropriate fit for study, to provide additional information, and to answer any questions. Initially fourteen persons responded to recruitment efforts. Of those potential participants, six were living with metastatic disease but were screened out because they had not lived past their expiration date. Three of those volunteering either became too ill or died before the initial interview could be conducted. Five female co-researchers were identified by the following inclusion/exclusion criteria:

- Each co-researcher self-identified themselves with having lived past their expiration date and were still living with a diagnosis of Stage IV cancer
- Each co-researcher was over 18 years of age.
- English was the native language for each co-researcher.
- None of the co-researchers were in hospice care at any time during the study.

- Each co-researcher was able to verbally articulate their feelings, thoughts, and perceptions in relation to the phenomenon as measured in a telephone or face-to-face brief conversation of 10 to 25 minutes. I asked potential participants about the circumstances that lead to their diagnosis. Through the initial conversation, I was able to obtain a sense of their ability and eagerness to express themselves openly about their experiences. This conversation also discussed the nature and purpose of the study, confidentiality, and voluntary participation.
- Each co-researcher was willing to create or find an expressive representation (visual art, poetry, music or musical lyrics) of their lived experience of the phenomenon

### *Data Collection*

Phenomenological data are the expressed naïve descriptions of each participant's lived experience and an exact record, in some format, of the description. Naïve means that the researcher brackets the research question and that the participant relates their experience from personal perception (Giorgi, 1985). The naïve descriptions, either in words or images, are generally collected through in-depth interviews when the "phenomena of interest is complex in structure and extensive in scope" and when seeking maximum depth, with minimal structure, to obtain rich, thick descriptions of the lived experience (Kyale, 1996 & Wertz, 2005, p. 171).

I adhered to the Epoche process before the gathering of data, during the interview process, and after the interview during the initial analyses of reflecting on the raw data (Moustakas, 1994). Before starting each interview I engaged in a brief meditative activity. The purpose of that activity was to increase the possibility of entering into the interviews with greater presence, mindfulness, openness, and authenticity as suggested by Moustakas (1994, p. 114). Data collection in this research occurred in two interviews.

#### *Data Collection- Interview One*

The first interview began with agreeing upon a time and place to meet for collecting data through a face-to-face open-ended, unstructured in-depth interview with each co-researcher. I met with each co-researcher at an agreed upon time at either their home or the primary researcher's private office. Immediately prior to the interview, I reviewed the informed consent form with each co-researcher and obtained her signature of consent. The co-researcher then completed a demographic information sheet selecting a pseudonym for confidentiality and a color for the purpose of coding. Information requested was for their name, age, gender, ethnicity, religion if any, national origin, general socioeconomic class, highest level of education, marital or partnership status, site and type of original cancer diagnosis, current status of cancer diagnosis, current status of treatments. (Appendix B) Participants volunteered to engage in the research after receiving information and informed consent. Each interview lasted between 70 and 120 minutes. All interviews were audio and video recorded. The interviewee was asked the research question "Please describe for me in the most detail you can, what is your experience of living past your expected time of death and still living with Stage IV cancer?" During the interview, I asked general clarifying questions

such as: Could you describe that in more detail? What was that like? How did that happen? Could you tell me more about that? Would you elaborate on that? I'm not sure I understood what you meant by that, please let me repeat to you what I think you said and please correct or elaborate on that. (See Appendix D: Interview Guideline: Clarifying Questions) Additional specific questions were spontaneously generated in response to what the co-researcher was describing. At the end of the interview, each co-researcher was encouraged to email or phone me later if they had more thoughts or statements they wanted to add to what they had expressed. Only one of the co-researchers had additional details she wanted to be added to her interview. This information was written into the record.

#### *Data Collection- Interview Two*

Some persons communicate better with images than words. "In recent years, there has been a growing trend in qualitative research to move beyond a strict dependence on the written and spoken word as the primary source of data" (Shank, 2002, p.142). Images are symbolic representations and can be metaphors for a description of a lived experience.

Since qualitative research is a systematic inquiry into meaning, metaphors are natural tools for leading us toward previously undiscovered modes of meaning...meaning reveals itself via things like metaphors, and part of our job as researchers... is to be committed to the notion that there is always more to understand. (Shank, 2002, p.121)

Creative arts as self-expression, expressed in any numerous manners, are equal to that of verbal expression. Expressive arts (visual art, music, movement, drama, and poetry) have been shown to be a positive experience for cancer patients, enhancing their psychological well-being (Borgman, 2002; Findlay, 2005; Garko, 1999; Gray, Sinding, Ivanofsky, 2000; Kahn,

1999; Pratt & Wood, 1998; Puig, 2006; Reynolds, 2003; Reynolds & Prior, 2006; Van Manen, 1990).

To bring words and images together, participants were asked to either find or create, through visual art, poetry, music, or lyrics, an expression of their lived experience of the phenomenon of living past her expected time of death and living with Stage IV cancer. Co-researchers did not request any art materials. The time it took to complete this endeavor was varied amongst the participants depending upon the current physical impact of their illness on their energy levels and with the use of fine motor hand abilities. The collection of this data spanned six months. Following the completion of their expressive representation, a second 30 to 60 minute meeting was scheduled for the collection of this phase two data. This meeting was held after the initial analysis of interview one data and after the co-researcher reviewed my first written description of their experience. The data collected at this time included a description of the lived experience of the phenomenon through a symbolic expressive representation. At this second meeting, I also asked any clarifying questions I had about the co-researcher's changes to the written textual description. As before in phase one, I engaged in the process of *Epoche* before starting the interview by bracketing the question in the meeting, practiced staying open to 'see and hear' new and unexpected facets, and attempted to remain as free as possible of preconceived probabilities.

I met with each co-researcher in their home for this second interview. I asked each co-researcher to show me their expressive representation and requested them to "Tell me about your expressive representation?" Each interview was audio recorded. Copies of the expressive representation took the form of a photograph, purchasing of music recording, and/or copying text.

### *Data Analysis*

Descriptions keep a phenomenon alive, illuminate its presence, accentuate its underlying meanings, enable the phenomenon to linger, retain its spirit, as near to its actual nature as possible. (Moustakas, 1994, p.59)

The data in this research was analyzed following the guidelines set forth by Moustakas' (1994) modified version of the Van Kaam Method. The analysis utilized three processes: phenomenological reduction, imaginative variation, and synthesis. Minor additions to this model are noted. The following outline (Moustakas, 1994, p.120-121) and brief explanations of the data analysis of all the steps are provided below.

#### *Phenomenological Reduction:*

Commencing with Epoche, the following steps were completed after each co-researcher's interview was completed and transcribed verbatim. Transcriptions included notations such as pauses, repetitions, false starts, interruptions, sighs, crying, and/or laughter. Each transcription changed identifying information by changing the co-researcher's name, names of others, and/or names of any mentioned locations.

*Step 1-* (Note this is a minor addition to Moustakas' written method) With each co-researcher's first interview, I listened to the audio-tape recording, reviewed video recording, and read through the verbatim transcription a few times while in the process of Epoche to garner a sense of the co-researcher's whole lived experience of the phenomenon.

*Step 2-* The first task of phenomenological reduction is “a process that involves a preflective description of things just as they appear and a reduction to what is horizontal and thematic” (p. 91). The process occurs through

- a. “Horizontalization” – For each co-researcher’s transcript I looked at the data and regarded every statement or horizon relevant to the topic and question as having equal value.
- b. Determine the Invariant Constituents. I queried each horizon: Does each statement contain a moment of the experience that is necessary and sufficient constituent for understanding it? Is it possible to abstract and label it? If -so, it became a horizon of the experience. Expressions not meeting the above requirements were eliminated. Vague expressions were presented in more exact descriptive terms. A minor change to the method outlined by Moustakas occurred here. Moustakas would have had all overlapping and repetitive expressions also eliminated. In this study, redundant statements were not automatically eliminated until I considered “that the ‘how’ of the appearance of a phenomenon may be as important as to ‘what’ appeared” (Giorgi, 2006, p.307). The statements that were left/the horizons became the invariant constituents of the experience.

*Step 3-* Clustering and Thematizing the Invariant Constituents: I then clustered the invariant constituents of the experience that were related into a thematic label. The clustered and labeled constituents became the central themes of the experience.



*Step 4-* Final Identification of the Invariant Constituents and Themes by Application:

Validation- I checked the invariant constituents and their accompanying theme against the complete record of the co-researcher to determine (1) Were they expressed explicitly in the complete transcription? (2) Were they compatible if not completely expressed? (3) If they were not explicit or compatible, they were deemed irrelevant to the co-researcher's experience and were deleted.

In steps 2-4 the researcher used NVivo a qualitative data computer assisted program (QDA) to organize data (Richards, 2006). NVivo does not have the ability to analyze the data or transform data into meaningful summations, nor did the phenomenological researcher desire such. NVivo cannot generate rich descriptions nor immerse in reflective thought with the data to discover the deeper essential features underlying a phenomenon. However, its strength lies in the program's capacity to sort, code, create diagrams and tables, and store large amounts of data in one place.

*Step 5-* Using the relevant, validated invariant constituents and themes, I constructed for each co-researcher an *Individualized Textural Description* (ITD) of the experience. I included verbatim examples from the transcribed interview.

*Step 6-* The researcher added an additional step at this juncture. At this stage the researcher provided to each co-researcher a copy of his/her ITD and was asked to check it for accuracy. If the co-researcher had new consciousness or disagreed with any aspect of the ITD, the researcher modified this accordingly.

*Step 7-* Steps 1-6 were repeated in analyzing the second interview. In the second interview, video recording was not done. Only new, non repetitive horizons and themes were added to the ITD. Each co-researcher was again asked to check it for accuracy and if necessary, subsequent modifications occurred.

*Step 8-* From all of the ITDs, a *Composite Textural Description* of all themes that emerged from each co-researcher's experience was composed.

#### *Imaginative Variation:*

*Step 9-* I then constructed for each co-researcher an *Individual Structural Description* of the experience based on the Individual Textural Description and using *Free Imaginative Variation* on each theme. Free Imaginative Variation has origins in the procedures Husserl developed to rigorously come to know essences; this is neither inductive nor deductive, it is the process of *eidetic* seeing (Giorgi, 1985; Valle, 1998; Wertz, 2005). Eidetic seeing is to descriptively delineate invariant characteristics and clarify meaning and the structure of a subject matter (Wertz, 2005). This was accomplished through the utilization of reflective imagination (imaginative variation) that enabled the researcher to take textural descriptions and derive structural themes in which the many possibilities were examined and explicated. The specific steps of Imaginative Variation included:

1. I systematically considered the underlying themes or contexts that account for the emergence of the phenomenon. I pondered the following: What conditions

or qualities are present to evoke this phenomenon? What must be present for an experience like this to happen? What might account for this individual's experience? How is that this experience?

2. I reflected on the universal structures that may have precipitated feelings and thoughts with reference to the phenomenon, such as the structure of time, space, bodily concerns, materiality, causality, relation to self, or relation to others.
3. I searched for polarities and possible variations that may underlie the textural meanings.
4. I allowed for free play in considering any possible structural dynamics that might have evoked the textural descriptions
5. I searched for exemplifications that vividly illustrated the invariant structural themes and facilitated the development of a structural description of the phenomenon" (Moustakas, 1994, p.99).

*Synthesis:*

*Step 10-* Engaging in the idiographic nature of the lived experience of the phenomenon, I created for each co-researcher a *Textural-Structural Description* of the meanings and essences of the experience, incorporating the invariant constituents and themes.

*Step 11-* I then engaged in a nomothetic description of the lived experience of the phenomenon. From all of the Individual Textural-Structural Descriptions, I developed

a *Synthesis: A Composite Textural-Structural Description* of the themes, meanings and essences of the experience that represented the group of co-researchers as a whole.

### *Strategies for Validating the Findings*

Validity of the study is derived from the perspective of the researcher, participant, and/or the readers of the account (Creswell, 2003; Fischer, 2006) To insure validity the following verification strategies were built into the study:

- Epoche-There is no absolute way to insure that the researcher will not be biased in some way, yet there are procedures that can assist the researcher with Epoche. Specific procedures the researcher followed included:
  1. Prior to conducting study, to help clarify biases, the researcher established a journal and wrote down preconceptions and leading questions to ask participants, to help clarify biases.
  2. During the study the researcher kept notes of suppositions, indicated biases, and missteps along the way in the journal
  3. Before each interview the researcher engaged in a solitary, brief centering meditation to allow for greater presence, mindfulness, and attunement to co-researcher.
  4. Before reflecting on raw data, the researcher was consciously mindful of coming to the data with naivety.

- The researcher used rich detailed first person descriptions exemplified through the actual text of the co-researcher. Rigor in a study occurs when the essences of the phenomenon are arrived at through honest and contextual descriptions which in turn make it possible for others to understand the lived experience (Creswell, 2003; Fischer, 2006; Moustakas, 1994).
- Member checking occurred in phase one of the data analysis by returning to the co-researcher with a written textural summary for modification or confirmation.

## Findings

### *Participants*

*Brynne* is a Caucasian woman who, at the time of the interview, is 59 years old and living with her significant partner of seven years. She has no children. Brynne holds a MS degree and has recently retired from her position of Executive Director and Consultant for an employees union and identifies her household income level as middle class. She currently claims no religious affiliation. She was originally diagnosed with early stage breast cancer in 1994, received treatment and was free of any evidence of cancer for five years. Brynne received a second diagnosis of early stage breast cancer in 1999, had surgery, and received chemotherapy treatment. After finishing treatment, she remained cancer free for three years. In 2002, she was diagnosed with Stage IV breast cancer metastases to her liver. At that time her prognosis for surviving terminal cancer was 2-4 years. To date, there have not been any additional metastases. Her treatments include conventional chemotherapy, cancer growth inhibitors, anti-anxiety medications as needed, and use of adjunctive complimentary medicine. Brynne's complimentary practices include an array of herbs and supplements taken orally or through infusion, acupuncture, psychotherapy, and other "healing" methods.

*Jo* is a Caucasian woman of Italian descent who was raised Catholic. She is 56 years old, at the time of the interview, and has been married for 27 years. She has a young adult child that currently lives outside the home. Jo completed high school and went on to work as a mortgage broker. She is currently retired and identifies her household income as middle class. Jo received a Stage IV cancer diagnosis 2002 without having any previous cancer diagnoses. Her cancer type was diagnosed as breast cancer metastases to the liver and in the blood

system. At the time of diagnosis she received chemotherapy and surgery. In 2003, Jo showed no evidence of disease which has continued to date. Currently, she is on lifetime management of disease receiving conventional treatment in the form of tablets and infusions of biological targeted cell therapies that use monospecific antibodies to interfere with cancer cell growth. Jo utilizes several CAM practices and takes prescribed sleeping and anti-anxiety medications as needed. Jo undergoes cancer detecting and heart toxicity scans every six months.

*Pearl* is a Caucasian woman of 56 years at time of interview. She has been married for 39 years and has two adult children that live out of the home. Holding a MS degree she has retired from all of her medical and educational consultant jobs. Pearl identifies her household income as middle class and identifies her religious affiliation as Jewish and Spiritualist. Pearl was first diagnosed with Stage III breast cancer in 1993. She received conventional treatment of surgery and chemotherapy followed by anti-estrogen drug. After finishing treatment she remained cancer free for 12 years. In 2005, she was diagnosed with Stage IV breast cancer metastases bilaterally to the lungs and the bones in her clavicle and ribs. Pearl has received and continues to be administered different combinations of chemotherapy drugs, drugs that help slow down the destruction of the bone, a hormone suppressor, and an anti-depressant. Pearl complements this treatment with physical exercise as she can, yoga, meditation, pet assisted therapy, naturopathy products, an anti-depressant, and counseling.

*Simone* is a Caucasian woman of 41 years at the time of interview. She lives with her husband of two years. She has a step-child who does not live primarily at her home. Simone has no religious affiliations. She holds a masters degree and is employed as a research assistant. She identifies her household income as middle class. Simone was diagnosed in 1996 with Stage

III breast cancer. At that time she received surgery, radiation, and chemotherapy treatment.

She remained cancer free for 6 ½ years. In 2003, Simone was diagnosed with Stage IV breast cancer metastases to the liver, lungs, and bones. She was administered aggressive chemotherapy drugs and massive radiation. Metastases to her liver and lungs went into remission soon after. Simone continued to receive several different rounds of chemotherapy drugs. Currently, having just completed (at time of interview) a round of chemotherapy, Simone's bones are also showing remission. She continues to take a drug to slow down bone destruction, takes an anti-depressant, and gets cancer detecting scans every three months.

*Christine* is a Caucasian woman of 52 years at time of interview. Christine has been married for 18 years and has no children. Christine graduated with a master's level degree and has held several different jobs. She currently is a self-employed owner in several businesses with her husband. Christine identifies the household income as middle class. Her religious affiliation is Jewish. Christine was diagnosed in 1993 with Stage II breast cancer. Her treatments then included surgery, radiation, and chemotherapy. Upon finishing treatment she remained cancer free for 7 years. In 2000, Christine was diagnosed with Stage IV breast cancer metastases to the bone. Over the last seven years she has endured many surgeries and chemotherapy regimens. Christine has just (at the time of interview) begun a new round of chemotherapy as her bone cancer has spread to new sites. She also receives monthly injections of an estrogen blocking agent, monthly injections of drugs to slow bone destruction, prescribed pain medications and an anti-depressant. Christine also utilizes complementary medicine in the form of acupuncture and naturopathy.



All of the co-researchers share many homogenous demographics in terms of race, gender, primary cancer site, socioeconomic level, and are all diagnosed with breast cancer metastases. However, the sites of breast cancer metastases, time lived since diagnosed with metastases, and the total lapse of time since initial diagnosis of breast cancer differ (see Table 1).

Table 1. Co-Researcher Demographics

Co-Researcher (pseudonym)	Age	Disease Status Breast Cancer Metastases	Time since initial diagnosis (years)	Time since metastases diagnosis (years)
Brynne	59	to liver	14	6
Pearl	56	to bones & lung	15	3½
Simone	41	to bones, liver & lungs (last 3 mos. in remission)	11	5
Christine	52	to bones	14	7
Jo	55	to liver. Currently NED	5	5

### *Individualized Textural Descriptions*

From each transcribed interview, the primary researcher distinguishes all the statements made by a co-researcher that are central to the experience of living with Stage IV cancer beyond one's expected death. These central statements, comprised of auditory, visual,

and tactile sensations, the awareness of and the meanings attributed to those sensations, are delineated as the horizons of the lived experience. This is the process of “horizontalizing,” the first step in the phenomenological reduction of the data that reveals the core invariant constituents of the phenomenon (Moustakas, 1994). The invariant constituents, expressed in the words of the participants, are the textural material that is drawn upon to create a written description for each co-researcher. In a state of openness the researcher returns again and again to the horizons of experience to delve deeply into the layers of the co-researcher’s experience with eye towards the thematic horizons emerging from the invariant constituents. The invariant constituents are then clustered into the identified core themes. These themes become the organizing framework from which the individual textural descriptions are composed. The individual textural descriptions of the experience of living past your expiration date and still living with Stage IV cancer were written by the primary researcher and then each co-researcher received a copy of their description for review. Any changes, additions and/or deletions were incorporated and the following textural descriptions are the results of this process.

*Individual Textural Description Jo: I can do it*

Jo’s experience of living past her expiration date and still living with Stage IV cancer is “not just one answer because it changes all the time.” The experience changes with each year that Jo outlives her prognosis and with each year that her scans show “no evidence of disease” (NED). At first, “I bought into my prognosis, and just accepted what the knowledgeable doctors and everyone in the field” described. She went from “believing I only had 12 to 18

months left to live... a really dark period... to thinking that I had maybe the possibility of living beyond my expiration date.” Once she outlived her prognosis, she “still thought and expected the disease to show itself.” As the years she survived have accumulated, Jo believed she could “continue to be NED but not totally, not like I do now.” The longer Jo lives with NED, the less she “buys into what she was told” and the statistics. And in turn, the greater is her confidence in thinking that “now, I really think I am going to stay NED for a long, long, long, time.” “I think I am probably going to be 80 something and die of something totally unrelated to cancer.”

Jo feels she is in a very different place than she was when first given a diagnosis of breast cancer metastases to her liver. Her doctor and everything she read “concurred” that when there is that much disease spreading not through “the lymph system,” but through “the route of the blood,” the longest expected survival time is “18 to 24 months.” “There was cancer coursing through my whole entire body.” “They [the doctors] never expected me to get in to remission.” She was told that the best possibility was to keep her alive long enough to “buy another two years of new treatments.” With the advent of new treatments coming out all the time, there was hope for another two years after that. Jo through out that time was “basically on the same drugs,” the same chemo drug, and then a newer biological targeted cell drug infusion every three weeks and a daily estrogen inhibitor were added later. Jo continues to receive the latter two drugs and due to the potential damage that one drug can cause, receives a heart scan every three months. What is different is that Jo decided to make a major change in her lifestyle and incorporate a variety of complementary care practices into her daily routine. This was in addition to following the Western medical model. Jo has been able to defy how her doctor explained that “cancer is really smart.” “The treatment may work for awhile

and [then] the cancer figures out how to become resistant to it” and returns. As a result, contrary to what was expected Jo has been living as a Stage IV cancer patient for the past “five years with no evidence of disease” showing on any of her scans. Unsure of what is working, Jo is definitely unwilling to relinquish conventional treatments to find out.

Jo believes that her longer term survival is not necessarily attributed to “luck.” “They say you have been so lucky. I guess I just want to investigate that. Has it really been lucky or have I earned it? I want to say, I know you think it is luck, but you know, I have done a whole litany of things that I think are responsible for getting me here and keeping me here. You won’t consider doing any of that stuff, so, until it is proven that I am not lucky, that I am on to something, don’t call me lucky.” “Maybe I wouldn’t mind be called lucky if I didn’t do anything, if I didn’t make a complete lifestyle change.”

One aspect of that lifestyle change is that Jo “totally changed the way I eat” and “changed what I eat.” She went “organic.” She tried a couple of different healthful diets “that have a lot of validity and I think have been meaningful for me.” Every morning she imbibes in a drink filled with “green powder, fresh fruit, pro-biotics, flax seed, [and] all kinds of stuff in it.” Additionally, Jo engages in guided imagery, practices affirmations daily “for a minimum of twenty minutes and some days lots more.” Jo has benefited from art classes, “vibrational healing” techniques, using a tone bowl, and other workshops geared towards healing. Jo considers these practices a “huge” component to staying in remission and when others ask about her survival, “I tell them what I’ve done that I think has been helpful. I feel really strongly that these things have, but I can’t convince any of my friends to do any of this stuff.” “I am thinking how bad do you want to beat this cancer.” “I wanted to do everything that had any impact on extending my life and I think people have to claim their power.”

One of the first things Jo did to claim her power was to give up the “stress from my life,” that came from working. Even though Jo felt that she was “really good” at her job, she gave up her lucrative career and with “all the money and all the wonderful things that money can give you, and my dream home that I dreamt of building for years and years and years and my beautiful garden, my Martha Stewart wantabe garden.” She also gave up “the taxes on the house [that] took two incomes.” Jo’s priorities shifted. Being “a top producer” in her field didn’t seem important anymore. “That’s where I used to be” but then one starts “realizing that life could be shorter,” one “could actually die.”

Jo’s relationship to death continues to change as she continues to outlive her prognosis. Initially, she “went through a preparing to die mode.” Jo spent the first three years really concentrating on “wanting to be less afraid of dying because I thought that was in the impending future, near future.” In seeking to be less fearful, “I went full bore into that and read everything I could get my hands on” about the dying process. “I went and got trained for hospice because I just felt that if I could be friends with death, then I wouldn’t have to be so afraid of it. So now I am in another place” where “I can’t say I’m not afraid of death at all,” but “I am not afraid of death like I was before.” At this time, Jo regards the “the act of dying, meaning like the whole six months or however long that takes,” with “the physical and emotional stuff...less important” and is far more curious about what happens after death.

When Jo thought she was going to die soon, she was still “a Catholic girl who bought into all that stuff.” Then she made new friends with cancer and became “interested in having conversations about religion” and in what they thought. Through these conversations, Jo lost her “trust and faith in Catholicism and I ended up going on this new journey” of trying to figure out what happens “after this life.” Jo feels she has made a “really big step” to get to

where she feels “okay” with the possibility that nothing happens. Yet, Jo continues to explore through “books,” “classes or seminars,” ideas about what happens after “your body stops beating.” Jo “believes that our body goes on,” and wonders about the connection with after life and the “power of intuition,” “psychic abilities,” and the work of “mediums.” But most importantly she desires to “start the conversation” with others who are “more in the same place that I am.”

As immediate death for Jo recedes, she experiences another change where “you go through that crisis where, oh gosh, who am I now? I’m not that successful, career person.” Jo is “trying to figure out what I am supposed to be doing. What my purpose is.” It is “something that I still need to pursue.” Jo has come to recognize that she has a strong “desire to help people.” Exploring several different options, Jo for now has settled on a volunteer position, at a local branch of a national association, to train persons to be cancer advocates for newly diagnosed patients. Jo tempers her pursuit of finding purpose by reflecting that “you can’t get too crazy with it.” “I think we put a lot of pressure on ourselves, you can’t be doing something meaningful all the time.” “Sometimes I stay in my jammies all day, read, bead, go work out, still doing the things that I said, boy when I retire, then I will have time and I can do this and do that.” “Maybe it’s just the whole dying thing... maybe this is just a bunch of stuff that we people have come up with to give our life meaning. So the best I can come up with is I do what I can to help people, cancer people...to be able to give them hope that they can do this too.” Then she feels like she has helped someone. “I think this is our basic need and our basic nature.”

As she progresses beyond her expiration date, Jo’s desire to help others also continues to shift. With the course of the disease, “certain things are going to be more

important to you based on where you are along on that path.” A few years back she helped form a support group for women with metastatic disease. Jo knows how this group is of benefit, though it no longer meets her needs. She has been “pulling away from group for awhile...it started last year when [my friend] died.” She doesn’t “want to make any new friends with Stage IV cancer” because ones that have said we are “not going anywhere. I am not going to die on you,” have died. Earlier, she “wanted to be able to talk to somebody” about her “fear of cancer coming back.” The longer Jo remains in remission, the more she feels that her good news “doesn’t feel right to share” with those who are more ill. Jo is feeling that she is in “a whole different place than everybody in the group” and is “lonely.” Feeling different and without purpose, “I just don’t think I can help anybody in group anymore,” creates within Jo a “need” “to form a new group...for people that have been NED for longer than two months.”

However, Jo has found few others with her similar experience. “When I was first diagnosed I just wanted to be able to see someone that actually had the same exact diagnosis as me and that was still alive maybe 18 months, two years or more.” And “whenever I meet people that do have the same disease as me, they are usually behind me in terms of being diagnosed with it in the liver.” For Jo, this is “really lonely because I can’t talk to anybody that I know about what it is like to be living without disease this long.” She searches and finds “nobody to talk about it or exchange ideas about where we are now.” “I don’t know anybody who has done the things that I have done.” “I seem to be the one who is always setting the pace.” “I am like I have to be the pioneer. I have to be the explorer.” Jo wonders if there is “somebody out there that has been NED as long.” Jo is therefore, looking towards forming a new NED group with “other women who had it in some organ, not bones, because you can

have it in your bones forever, but somebody that has had it an organ and that has been in remission as long as me.”

Being “goal oriented, result oriented,” Jo is searching for a group of people who will want to talk about their attitudes towards cancer and perhaps discover that there are “a lot of the things that we do or think along the same lines.” She wants to know if with others there is any commonality tied to being NED: “Is he doing the green drink? Is he drinking tons of ionized water? Is she doing guided imagery?” “I would want to know what their practices are. Do they have any type of spiritual practice... do guided imagery and vibrational healing?” She wants to know how it is that she survived, “why me,” and what she can attribute to surviving this long. She believes that “If I found somebody that has pretty much done a lot of the same things that I’ve done and that they have been NED, it would just kind of confirm that I need to keep doing these things.” It would give Jo a “good feeling” to know that there are other people “who are doing things that I am doing...and maybe some things I am not doing.” Jo wants a new support group where people are “able to stay committed...to walk the walk” of being committed to trying a more rigorous complimentary regimen.

Jo wants to find others with whom she would be able to share whatever it is that she is experiencing. With a diagnosis of Stage IV cancer and being NED, Jo sees that “life is just a series of phases” in which her experience of it is “just always changing, always changing.” And amidst all those changes, “I realize that I’m always looking for some companionship along the way to talk about the way you are feeling and knowing that somebody else is either struggling with the same things or having a similar experience.”



An analysis of the horizontal statements in Jo's interview revealed the following central themes:

- ◇ Death
- ◇ NED and CAM
- ◇ Lifestyle changes
- ◇ Spirituality, meaning and purpose
- ◇ Relationship to others
- ◇ Beliefs
- ◇ Changes

*Jo's Expressive Representation: I believe I can fly*

Jo chose the song "I believe I can fly," by Yolanda Adams as an expressive representation for her experience of living past your expiration date and still living with Stage IV cancer. The lyrics of this song follow (see Figure 1). Hearing the music that goes with the lyrics is powerful. The significance of the music is described by Jo:

When they start out they are talking about how horrible things were happening to them, and they were really at this very low point in their life, and then something happened where they were made to believe that they could do it. It just really spoke to me because my whole life, which I know I have said to you a number of times during our couple of meetings, is that show me somebody who did whatever it is that supposedly can't be done, and if they can do it, I can do it. ... That song popped into my head, after I went through the holy crap, I am going to die, there is nothing I can do about it. ... This is not R. Kelley, but I went out looking for his song and for some reason found it on this gospel music CD. The guy at the store was saying, oh, if you like the way R. Kelley did it, wait until you hear these gospel singers do it. Anyway, I bought it and it was sort of like my theme song. I play it every morning.

<p><b>I Believe I Can Fly Lyrics</b></p> <p><b>Artist - Yolanda Adams</b>  <b>Album - Various Songs</b>  <b>Lyrics - I Believe I Can Fly</b></p> <p>Verse 1: Be Be Winans</p> <p>I used to think that I could not go on  And life was nothing but an awful song  But now I know the meaning of true love  I'm leaning on the ever lasting arms</p> <p>Bridge:  If I can see it  Then I can do it  If I just believe it  There's nothing to it</p> <p>Chorus:  I believe I can fly  I believe I can touch the sky  I think about it every night and day  spread my wings and fly away  I believe I can soar  I see me running through that open door  I believe I can fly (x 3)</p> <p>Verse 2: Yolanda Adams</p> <p>See I was on the verge of breaking down  Sometimes the silence could seem so  loud  There are miracles in life I must achieve</p>	<p>But first it's got to start inside of me</p> <p>(Bridge)</p> <p>(Chorus)</p> <p>Cuz I believe in me,  yea, yea, oh, oh, oh, oh, oh</p> <p>Yolanda Adams:  If I can see it</p> <p>Be Be Winans:  Then I can do it</p> <p>Yolanda Adams:  If I just believe it</p> <p>Be Be Winans:  There's nothing to it, oh</p> <p>(Chorus)</p> <p>I believe I can fly (I can fly) x 3  I can do anything yea, yea, yea, yea  I can fly x 3  I can do anything, yea, yea, yea</p> <p>Anything I wanna do (Anything I wanna  do) x 3  I can do anything  I can fly</p>
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Figure 1. Jo Expressive Representation

*Pearl's Individual Textural Description: A conundrum*

Pearl experiences living past the time expected and still living with Stage IV cancer as “a challenge,” that is “confusing,” and “weird,” though mostly it is “really a conundrum that you grapple with.” It is a conundrum that surfaces in the wondering of “am I living and knowing more about my dying than others do, or am I dying but in the meantime I have to continue to live.” In living with death, Pearl “thinks” that “there are different components to the question of how to live after you have been diagnosed with a terminal or non-curable condition.” Those components consist of living with considering how to walk the “fine line between self-care and selfishness,” limited by “profound fatigue” and experiencing emotions of “anger without the filters,” “guilt,” “frustration,” “fear,” “sadness,” and “feeling inert.”

It’s a conundrum in living with a drastic change in how she lives daily life with not working anymore and “without goals.” Pearl was “somebody who used to do more between 5:00 am and 10:00 am than most people do all day.” “I was very high energy, high profile, get a lot of stuff done and never felt that” it was so hard. For Pearl, “it is confusing, because I am pretty straight ahead, kind of take charge, move forward kind of person” and now she feels like “I’m not doing anything.” In this conundrum Pearl wonders that if she was living her last six months “did I do in those six months what I would want to do. And yet since I don’t really believe that they are my last six months, I’m not getting stuff done.” Pearl has the fear that she is going to come up “short.” “And people are going to say, my god, she had three fucking years to get her stuff in order and look at the mess she has left behind.” It’s that “double bind of wanting to get stuff done, but not wanting to do it too soon.” Pearl wants to do certain things before she dies, “not like go to the Grand Canyon or the Eiffel Tower, but re-

alphabetize my spices” and “clean out my closet.” Pearl wants to “get rid of some of this shit.” She wants to be “tidy” and prepare herself just as much as she wants to lessen the impact that her dying and death will have on her family. She worries about burdening someone with having to go through all of her things that she may leave behind. As she tries to anticipate what she will want to wear in the next season, there is a part of her that thinks she may not even be here next summer. And, she has “already experienced giving away stuff prematurely” finding that she still wants those items. This dilemma places Pearl in a position in which “I spend a lot of time standing in my closet, planning to clean it out, and then I don’t do it.” It is a “sense of inertia” in which Pearl wants “to be prepared, but you don’t want to prepare too soon.” “It’s a timing thing.”

On the other hand, in dying while living, Pearl’s experience is that once diagnosed with Stage IV cancer, no matter what she does, the “cancer has its own mind.” She believes she has some influence over staying as fit as possible to lessen the impact, but that this will not alter cancer’s agenda. Pearl lives with the “constant concern” that she will be caught off guard by a sudden, spontaneous acceleration of the cancer without having had time to prepare for it, before she has had time to “wrap up things.” “I think that is a fear that I have, that that spontaneous thing will happen and I won’t have the prep for it.” While Pearl doesn’t want to prepare too soon, she also doesn’t “want to wake up to a surprise.” Pearl believes she could “deal with any of this” if she could know the timetable. “And, of course the definition of cancer is chaos so you don’t know...It is very frustrating.” “I would categorize this whole thing as really a conundrum. In the beginning I kept saying my biggest challenge is trying to wrap my head around this. I think that that hasn’t changed.”

In the beginning, when Pearl was diagnosed with Stage IV cancer, all of the research

she was able to come across pointed to “a mean survival rate of two years.” “So that is what I set my mind on.” For the “first four or six months,” “there was this really heavy focus on dying and what I was going to be doing and I needed to prepare for that and to prepare my family members for that.” With a diagnosis of cancer metastases, Pearl “didn’t go through the same stages that I went through the first time.” The first time when she was diagnosed with breast cancer, Pearl “felt betrayed by my body. I felt betrayed by data and information, health education. I just felt like how could this be happening to me when I wasn’t at risk by traditional risk factors. ...The first time I was diagnosed, maybe because I was younger and I had an active family in the house, I was very angry, very angry, because I had been health conscious all my life – physically active, no drugs, no alcohol. I had quit smoking when they said smoking was bad.” With the first diagnosis, Pearl worried for her children and turned towards religious beliefs. She believed she could bargain and she “made a deal with God” to live long enough to “shepherd” her young adult child through life a “little longer.” Pearl survived longer and her child has grown. With the “re-diagnosis of Stage IV cancer,” when Pearl consulted a rabbi about her “deal,” she was told that “God doesn’t make deals. Things happen, but he doesn’t make deals. You don’t get to boss him around and say when you get to die. So I wasn’t angry. I was profoundly sad.” “This time it was as if, aha, I already knew this was coming, yet I had never really verbalized that before, that I was expecting a re-occurrence or wanting a re-occurrence.” “It wasn’t as anger-producing.” This time “it was more like I was paying a bill.” “I felt as if I had really lived a pretty good life and I just wasn’t all that freaked about it.” “But I was on a mission to die.”

The mission to die included Pearl wondering about “what do you wear; who does the eulogy; what kind of flowers; music.” Pearl was “searching” and “must have read 50 books on

death and dying. I wanted the checklist. I wanted the to-do list and it doesn't really exist."

With her own list Pearl "bought an iPod to organize my memorial music. I tried to put it in a PowerPoint. I was using my typical educator skills." "I was just on a mission." "I was kind of angry when people would say, but, you know, you might not die. I was like, well, of course I will, on time, on schedule. I am never tardy. That was the beginning of it."

After a while, after witnessing others live longer and more actively with Stage IV cancer, Pearl thought maybe her "paradigm was wrong." "Maybe you do get to live with this process longer. Then I started thinking about living with this terminal diagnosis and managing it like a chronic disease. I started pulling in other resources of wellness skills- yoga, meditation, exercise, and changing diet, but not inconsistent with how I had already lived." Pearl's management includes a "medical scenario" in which "every 90 days I progress" just as she gets her "hopes" "not up, but out of the doldrums." Pearl in the doldrums experiences emotional stress, physical fatigue, insomnia, times of nausea and vomiting, diarrhea, weight gain, and the painful hand and foot syndrome where her extremities "get red, blister, crack, [and] the nails turn black and fall off." These are the cumulative "incremental side effects" from both the cancer disease and the course of treatments. Out of the doldrums for Pearl is the "realization" that it wasn't until she felt good, had her energy back and could say to herself "I can do this," that she recognized "just how bad I had felt before." Out of the doldrums also meant that her tumor markers were dropping. Then her meds stopped working "and in a very short period of time my tumor progressed again and we had to switch medications." "Then it [the scenario] happens again." "Irrespective of what we throw at it, no matter how noxious the treatment, how hard the side effect, the tumor seems to have its own timetable and it is progressing." There in the timetable lies an aspect of the conundrum, the not knowing just how slow or fast

is the cancer progression. Pearl's experience of living and dying is epitomized in her "metaphor for cancer" that she had when participating in a triathlon: "You don't know how far you have to go. You don't know how far along on the process you are. You don't know if you are going as fast as everybody else or slower. You don't have any idea." Along the route, Pearl experiences profound fatigue and tries to "not let the adrenalin burn out."

In the beginning Pearl believed that death would be more rapid. "Now, I have had the experience of seeing the progression of my cancer being somewhat slow in comparison" to others diagnosed with terminal cancer. Yet Pearl lives in this conundrum that, "you know, all this doubling could happen really rapidly and I could be kind of unaware of it for 90 days and then all of a sudden be really sick, or have a side effect come up – an infection or a renal shutdown or something." Pearl is afraid that she might "get duped again by my body." Duped is "that body betrayal where it builds cancer and it doesn't tell you, because I don't really have much symptom from my cancer." "It seems slow to my doctors, but when it is growing inside your body it doesn't seem slow." This sense of betrayal for Pearl extends to doctors and cancer technology. "The medical scenarios we have created for me have not worked." "Getting into the habit of expecting it to not work" gives Pearl the "feeling that all of it is in limbo." "I think I come to that a little bit even counter to what my physician says, because my experience with cancer with physicians is that they are always a day late and a dollar short to me." The first time Pearl was diagnosed her doctors told her that she "was just behaving hysterically and I had nothing, and meanwhile I had a Stage III C cancer which they told me was a stage two." As a result Pearl feels she has been "either lied to or under-frightened by doctors" "because I've been told I have been doing fine when I have been doing really bad in the past." Pearl's current oncologist "is really an optimist and always says all these wonderful things but he also

said, in December, that I was fine. In February I was Stage IV.” Pearl does not hold this physician responsible because she had no symptoms. While at the same time she thinks “the technology in oncology is not sophisticated enough for early enough detection of any progress until you have pain. Until you have a lump or a bump, until you have overt bleeding or really overt objective clinical symptoms, they don’t follow up.” “So the fact that he tells me I’m doing fine doesn’t give me the reassurance” it gives others.

Pearl is not as “hopeful for a cure” and feels different than others in her situation who “seem to still believe in some cure for themselves.” “I do not believe in an opportunity for a cure based on the facts.” Pearl believes that others with Stage IV cancer are at “different places with their acceptance of what is to come, their management of time in between,” and in greater “denial” than is she about dying. “I think I get that part of it more than others.” Pearl doesn’t see cancer as a gift and “I have never saw it as an opportunity to improve my priorities or straighten my life out, because I always felt like my life was in a pretty good place and working toward some pretty decent goals.” A friend gave Pearl one of her favorite “crazy, sexy, cancer tips:” “cancer is not a gift, because if it was who would I put a bow on and give it to. Nobody I cared for.”

Pearl also finds it “challenging” to be with people who are not survivors “because they all want you to get better.” “They all want to believe that cancer is curable because they see on television that we are racing for a cure.” It is even more difficult for others to grasp the nature of the illness” now that she has her hair back and looks fit. “I’ve spent a lifetime exercising, eating well, taking care of my body, so I have the benefit residual of having a really terrifically fit, healthy body, other than the fact that it is full of cancer.” “People say you look terrific.” Part of the conundrum is in Pearl’s not knowing “whether I am glad I look terrific or whether



I wished I looked non-terrific so that people would give me more empathy and pity.” “What do you do with that? Do you want to stop and explain?” For Pearl the explanation would also include that she believes that “we have fouled our nest irreparably and the cancer is the canary.” Pearl wishes she had the “strength and the mental fortitude” to clear up “the myths and misconceptions that perpetuate” but “some days there is just not time or energy to straighten the world out.” Pearl looks towards “the metaphysical level” believing that “there must be some good coming out this experience for me” and for others who are in this experience. She searches for the rationale to “why am I going through this experience in particular.” She ponders if it is to use her “resources and skills” “to be the role model, the articulate one” or if she “should do this on a more private, person level” and “vacillates between the two.” Some days she is “more willing to be public” while on other days she is just “wanting to sit on my pity-pot.” Pearl considers the “global piece that I feel compelled to dabble in” and then thinks about “the micro piece which says what am I going to do today.”

On many days Pearl doesn’t “even get out of my jammies. I get up and I stay up in my pajamas half the day and then it is time to go to bed again and I don’t even change them. That is a whole new concept.” “I don’t say, well, you should get up when you don’t feel well and do things.” “But on the other side,” Pearl is in a quandary because “it still feels a lot like inertia to me just because I don’t get up and put on the stockings and heels every day like I did before.” “It feels like I am lazy or slacking.” “It feels like I am not doing anything.” She is “used to being very task oriented.” “I used to have very clear goals, either professionally or personally and those things are gone.” Pearl believes that most people “have this general sense of an out-there timeframe that you are moving towards.” “I am going to go here, I am going to accomplish this. When I retire I’ll do that.” For Pearl, “in my world that is all gone. There is no

planning for the future.” There is no “goal setting.” As a result, “I feel like I am not accomplishing things” “because I am not working toward a goal.” “Because I am not moving toward a goal, I feel inert.”

Pearl recognizes that “while cancer doesn’t define me, I let it restrain me.” “Part of my worry with this diagnosis is that I will do well long term,” “live long and have done nothing and been prepared to die for so long that I allow that to be the rest of my life.” Pearl is afraid that she will “look back” and “be really resentful that I didn’t do some things” that she had wanted to do. “There are things that I am not doing because I think I am dying.” “Then I feel like I have this time, this gift of time and I am wasting it because I am not doing the things that I would want to get done.” Getting things done refers to accomplishment for Pearl. In the past accomplishing meant “growing her business,” “getting recognition and economic reimbursement for her work.” So Pearl questions herself on those days that “are just regular go to the store, cook dinner, feed the dog,” days consisting of “the simple pleasures of the things I like to do,” if she is wasting time. “Like how *do* my days pass.” “It is really weird, it is just weird.” Pearl in reflecting on the phrase “make each day count” asks “how do you count” the days and “how do you make it [each day] count.”

Adding to the puzzle are those times, Pearl may feel good enough to “plan for a marathon,” for “sewing,” or for entertaining guests at her house. But then Pearl feels “apologetic” in those times of activity for “that extra cognitive burden that you bring to everyplace you go” because she experiences everyone treating her differently because of the cancer. Those times are often compounded by feeling “guilty.” Pearl feels that she is “taking up other people’s time, psychic energy.” As a result, Pearl feels “this compulsion to minimize what I am doing, because I don’t want people to feel like, well, she is asking for all this slack

because she is dying and then she is out living this large life.”

Pearl feels guilty because she is not working at her many business ventures. Yet she could not continue to work because she could not predict how she would fare physically. In one of her business ventures, Pearl could not foresee if she would be able to “sleep the night before,” or if she would “wake up with a bad case of diarrhea.” And she found herself forgetting too many of the fundamental tasks that helped her perform well. Pearl did not think she could “obligate” herself to something she could not fulfill. Being “depended on” “was something that I was famous for.” “It is that sense of irresponsibility or undependability that makes me say no to the work.” In another business she owns, Pearl feels guilty because she is not working and still receives some funds. She stepped away because she found herself losing empathy and “resenting” the “non cancer” clients who talked about their “hyper-neurotic” troubles. Pearl had difficulty “being nice” to her staff and would get “angry” when they did not meet “clearly delineated procedures” not because she views it as “my wanting to control how everything is done. I just want everything done right.” Pearl stepped away from work “because I was going to destroy other people.” Her “filters were thin” and anger was expressed outwardly. Pearls’ anger arises from not being able to preside over her disease. Pearl is used to “having things that I can learn, and then once I learn them, I can do them and I can excel at them and then I can teach others.” It is the “getting it right piece.” But with cancer, “there is no protocol.” “Cancer is something that you can’t control. You don’t get to say no. I don’t get to say no to treatments. I don’t get to say no to doctors’ appointments. I don’t get to say no to anything anymore.” “Cancer is my life. Every day I take medicines that are related to cancer.” Pearl has few non cancer interludes and finds that almost everything she engages in is cancer related. She thinks about activities where cancer isn’t the focus and surmises that “I don’t have

enough of that.”

In her cancer world, Pearl also feels guilt emerge “around the notion of being selfish.” She is trying to distinguish between taking care of her needs and caring for the needs of others. Pearl “intellectually” “understands that I need to take care of myself” and believes that “I am probably living longer because of self care.” Yet Pearl believes that conserving her resources “energetically and emotionally, physically for my own self” is “selfish” and requires “putting up boundaries which I was never very good at.” “It’s difficult stuff” to do what she wants to do and put “my needs before somebody else’s.” “People are always saying, well, do whatever you want.” “Well, that is all fine and good if you die fairly quickly and you don’t burn all your bridges. But if you keep doing everything you want, irrespective of what others want, then fairly soon, that won’t be how I would want to be.” Pearl values an “act of selflessness” over being selfish. “Not that I am a big Mother Teresa but I think I’ve generally chosen others and then found my own happiness in that.” In living longer than expected with terminal cancer “you have decisions to make all day long that make you choose between yourself and others” and that’s “a really hard one.”

In the conundrum of dying while having to continue to live past the time expected, Pearl says she does not have any fear of death itself. Though she does have “an interest and curiosity” about “what happens to my energy or not.” For her, that is the part “where it gets better for me at the end because I have a spiritual faith and a universal sense of energy.” Most recently, Pearl has begun a daily yoga practice. Pearl’s new practice that incorporates “Dharma discussions” creates a way for her to connect to her spirituality on a different plane. In studying the “yoga sutras and the yamas,” Pearl resonates with a changed understanding of the “five reasons we suffer- attachment and aversion and impermanence and those kinds of

things.” Through this daily yoga practice Pearl has opened herself to moments of “flow” that provide her with a sense of connection with a universal energy and sense of harmony in time. These moments add to Pearl’s beliefs about death. Pearl believes “that the essence of a person or the essence of your soul, whatever language you want to put to it, is neither created or destroyed.” In death then, “whatever will be, will be.” “I don’t have any idea what it is” and she is “not concerned about that at all.”

Pearl is concerned about friends and family. “In the beginning, the first few days” “I think the hardest part” was “telling people you love.” Now, “the hardest part is to watch the impact my cancer is having on the people who care about me” and “I would rather protect them from that.” In protecting her loved ones, Pearl filters what she tells her family. “There is no need for them to know test result to test result...unless they ask.” “Toward the very end, there will be enough in-your-face shit for my family.” “So during the interim it doesn’t have to be rubbed in their nose every day.” Pearl expresses particular worry for her husband. “I am concerned about the impact on my husband and his ability to grieve and be happy afterwards.” “We have a good marriage and good friendship and I am concerned that he will be so profoundly sad. ...So I just want to make sure that there are people checking in on him.” With her adult children, she feels “very sad that I complicated their lives.” Pearl worries about how her grandchildren will handle the information about the process of her dying and death. Pearl doesn’t “want to control things from the grave, but I would like to make things easier for my family afterwards.” “I really want to somehow do this in a way that is enlightening” for them “so that it feels like a natural process, that this is part of what happens in life and this is okay.” She is “concerned about the examples and the lessons” she can impart to them about death. She especially wants “the process to be somewhat healing” for one of her adult children.

Pearl knows that “cancer is not a clean death” and she would prefer “not to elongate it.” In order to make the end easier for herself and family, Pearl has delegated tasks to certain friends. “I have friends who have sort of been given assignments. When I die this is what I need for you to do. When I take to my bed, I need you to do this. I need you to manage this. I have had some of those really nice and hard conversations with my friends, early on.” Pearl has many friends and the “best part of this experience” is that “there have been great people along the way that I may not have encountered in the same way. There has been an incredible outpouring of friendship from people who are my friends.” “And now they verbalize what I mean to them. So it is really nice to get to sort of be present at your eulogies on a day-to-day basis when people share nice things with you.” It is all part of “living with knowing about your dying.”

An analysis of the horizontal statements in Pearl’s interview revealed the following central themes:

- ◇ Death
- ◇ The conundrum of time
- ◇ How to live while dying
- ◇ Role of CAM
- ◇ How to prepare for dying while living
- ◇ Physical, emotional, and cultural impact of terminal cancer
- ◇ Former self-identity and relationship to work
- ◇ Beliefs, values, and strategies

- ◇ Relationship with others
- ◇ Spirituality
- ◇ Meaning
- ◇ Changes over time

*Pearl's Expressive Representation (1): The Fall of Freddy the Leaf Quilt*

Pearl chose to create a quilt to represent her experience of the phenomenon (see Figure 2). She described the process and the significance of the expression and representation:

I don't consider myself creative artistically, but I am an avid quilter. I look at quilting more like math, geometry and science. I look at color as percentage of saturation, deep saturation, light tones. To me that is a function of some sort of physics, light saturation. The actual cutting is math. How many little triangles do you get out of a yard and how do you put them back together to make a two-yard quilt. ...As I was working on it [this quilt] and picking the colors and picking the layout, I was reminded of this Leo Bascaglia story, *The Fall of Freddy the Leaf*, which is a story of life and renew and death through the eyes of a leaf. ...As I started doing the layout for this quilt, the final, where each square was going to go...I ended up putting the darkest leaves sort of in the center, sort of representing the end stage of Freddy's life, when he actually turned very dark and brittle and fell from the tree. There are some where there is different stages of color. ...The quilt became very symbolic to me in that this death, or this letting go of the limb became the central piece and then all the different phases of it are somewhat scattered around the quilt. That was sort of the thinking. I did a label for it –The Fall of Freddy the Leaf. ...All of my relatives that came from Russia were tailors and seamstresses. I had forgotten the tradition of sewing and how far back it went in our family. Maybe I come to this tactile thing with fabric and texture and textiles from some old country journey, to touch the fabric, and piece the things together. ...I keep the quilt out in the living room and the book adjacent to it, so if somebody was sitting down, having a cup of tea, a guest or whatever, part of my thinking was that at some point down the road, when I am not here anymore, somebody is going to catch on to that and go, oh, she was pretty funny. She has the book there, then she made the quilt and she named it the same, oh, I get it. ...[They will get that] I was trying to tell them stuff about it, and that it is okay, that it is comforting. You can snuggle up with it. ...They will just be sitting there one day and go, oh, mom was trying to tell us something, or this is why she did

these quilts. They had meaning to her. ...Part of the concept here was my constant desire to communicate with my family or my friends in a way that is not only verbal, but symbolic. As much as I am a big talker, there is a lot of symbolism in many things I do, and so this is really very symbolic of teaching, trying to let my family learn that everything can be okay, and that book certainly – in the book everything ends okay.



Figure 2. Pearl Expressive Representation (1)



*Pearl's Expressive Representation (2): Tattoo*

Pearl also wanted to share her recently completed tattoo as a second expressive representation of her experience of living past the expiration date and still living with Stage IV cancer (see Figure 3). Pearl described the planning and expression of her tattoo:

I thought about all my objections to tattoos. One is it is going to be on you forever. Well, forever isn't so long anymore. ...Then I thought where on my body. I had several months to plan this out-where and how big. I started collecting some stuff on the web and I found these beautiful yoga people in this tree pose and mountain pose. Then I found these great musical notes and treble clefs...that reminded me of ...the music in our family. The yoga people sort of represented my friends, even my friends who don't do yoga, but that whole supportiveness of friends. ...[there is the] symbol... the African symbol of resiliency and fortitude. One who wards the symbol has overcome much ...it is in the center, and around it are the people, woven into this filigree – you can't really see them unless you look for them – and underneath is the musical notes and the whole flow of it is symbolic of the treble clef, even though there is not really a treble clef there. To me it says, based on the love and support of my family and my friends, I have been able to have this amazing fortitude and resilience.



Figure 3. Pearl Expressive Representation (2)

*Brynne's Individual Textural Description: It's a journey*

Brynne's experience of living past her expiration date and still living with Stage IV cancer is of a "journey." The journey described as "complex," is often experienced as being on a "roller coaster," and "all over the map," but a "really full experience." Along the way, Brynne has learned to think that "nobody's life is just this beautiful plane of sunshine. We each have our challenges, and this is mine." And through this journey, she has "learned more in these five years about myself in real depth, about my core spirituality, what I really believe, than in the first 50 years of my life. I now truly experience my connections to the universe." The map of this cancer journey "is not just a straight path, it winds and turns," and sometimes circles back around. Within the landscape, there are "magical places, really hard things and growth times," where hope is interwoven at every twist and joy supersedes to provide her with a more enhanced quality of life. "The joyous, the really good, wonderful times outweigh the really terrible times."

Brynne's cancer journey is infused with joy and hope. "It is joy at every moment. It is joy at living longer than I thought I would. It is joy at living longer than I thought I would and still having my cancer be about the same." Brynne has not had lesions outside her liver. "It is just the same ones [tumors] that get bigger or get smaller or become inactive. So it gives me the feelings of hope." Brynne feels hopeful that there are still other treatment choices for her and that she seems to respond to everything for awhile. Brynne's hope centers on whether she will be "alive long enough to be a part of whatever new things they discover, on the Western medicine front, that change the nature of the disease." "She knows there are persons living who have had "no evidence of disease for 20 years or more, who had a very similar disease as

mine.” Brynne hopes that if one person can outlive their prognosis for that length of time, perhaps, she could too. Brynne believes that is possible because “our body/mind can heal itself.” “Whether that will happen for me or not, I don’t know, but I believe it can happen.” Brynne hopes to die from something other than cancer. She doesn’t see herself as a “Pollyanna person” who denies the terminality of her disease. “Clearly I accept that. But I also refuse to give up hope.” “Hope has always been with me” “Over the these many years it has been hard for me to get really depressed that I have Stage IV cancer” for “I think that every day is beautiful and every day is so meaningful.” “There is so much magic and so much joy in this world in which we live.” Though there are times that require her to work psychologically harder to remain optimistic and positive, especially when she considers “what the treatments are doing to me.” Reminding herself that “it’s only been six years since my metastases diagnosis, 16 years since my original breast cancer, which apparently wasn’t enough to get my attention then, so it makes me have to work harder to stay in the place that I am, where I believe.”

The roller coaster on which Brynne finds herself living from day to day on a variety of emotional and physical planes depends upon which situation in an intricate, multifaceted maze of treatments, side effects, and/or tumor size she is confronting. It also depends upon “how good I feel about where I am going, and the focus and depth of meditation I am doing to help myself.” On the physical plane, the ride depends upon available treatments both conventional and complementary, “what drugs are out there and looking at what new things are happening, what are the choices, what are the side effects.” There are great days and “hard days.” “These really great days I am having right now might be really different in another month or two.” The side effects from treatments are not always so tolerable. There are days

when she feels physically “really bad because of the drugs.” There are nausea, mouth blisters, fatigue, intestinal cramping, bowel and neuropathy hurdles. There is “fatigue and hand neuropathy” that prevents her from finishing projects she enthusiastically began. There are weeks of non stop diarrhea where even getting out of bed is difficult. For “a few weeks when I started this one [drug], I got up one morning and I couldn’t walk, my feet were so messed up.” That particular side effect “scared me because walking is one of my joys.” Those are the times when emotions and thoughts other than joy come to the foreground.

On the emotional plane, Brynne has learned how to express her emotions and does so more often. She has learned how to shed more tears and not “to stuff my anger.” When Brynne’s cancer goes into remission and then in only a few months “comes back,” she gets “really frustrated.” “Sometimes I am feeling frustrated because I think I’ve really dealt with a lot of issues, and I shouldn’t have this cancer anymore.” Yet, there is “growth that comes from doing the work connected with having cancer.” “I know the work that I’m doing is helping me grow more beautifully, but I don’t get to experience it fully until the brief times I am off the drugs.” Every time Brynne stops the chemo for awhile and coalesces what she has learned, she begins “feeling really good” and “living on a whole, more wonderful transformational level.” “Then I get two or three months of just feeling wonderful and alive.” Intermingled with losses, she grasps the magic and gifts cancer metastases has brought her.

Brynne doesn’t think of cancer as a “gift” to give to someone, yet she appreciates how cancer has bestowed her with opportunities to gain new insights and to find days of joy and awe. One such gift was in having to receive “disability benefits” because she couldn’t do her job anymore. “On the one hand it was really devastating.” “I had 15 years of my life of my heart invested in it [the job], but it was really, really bad for me” with long hours and high

stress. “So for me, not working was hard to get to and hard financially, too, but the gift of waking up every day and knowing that this is my day and I decide what is in it, there is magic in that, because it helps me make decisions from the heart.” “The fact that I can go for a walk anytime I want. That I can turn on music and twirl around the room if I want to. That I can sit and be quiet and meditate any hour. I don’t have to try to cram it in before or after work. I can see friends and there is a gift in that.” It is the gift of having more time to figure things out, “to make peace, to do things that are joyous and loving.”

Another gift for Brynne is having “great insurance coverage” for “another six years.” Her insurance covers the costs of Western and complementary care that most other people’s insurance does not. If she is not “healed in six years,” Brynne has a plan. She is trying to sell her house so that she can “have a little pot of money” to investigate the “cutting edge things with vaccines and mistletoe” that are being studied in other parts of the country. Brynne reflects on this, understanding that Western medicine “is about how long you are going to live and not about can we cure you,” and believes that she needs to “to fully, fully explore complementary medicine, because that seems to be where more of the long remissions or cures, in quotes, are happening.” Brynne finds support for this belief in feeling that her experience is “less traumatic” because she is “so fortunate to have a pretty indolent set of tumors instead of more aggressive ones. But, I don’t know how much of that is because of the complimentary things I am doing. They may not be taking the cancer away, but they are helping with making them grow more slowly and me feel better in the process.”

Brynne speaks of the gift of relationships of having a “wonderful healing circle of practitioners that keep me well, keep me feeling well, keep my spirits in a good place, who just support me.” Although she has lost members of her family and some friends to cancer, “too

many recently,” she delights in the gift of having “a wonderful family and wonderful friends.” Maintaining those friendships at the times when she is most impacted by treatment requires Brynne to “work really hard not to become reclusive.” She encourages herself to get out to socialize, “interact with people,” “travel,” or be “in the garden.” Brynne is most appreciative of having found her “soul mate,” “a wonderful partner who is the biggest gift to me in the world.” It’s “having unconditional love in my life and being able to give unconditional love that is so remarkable.” However, there are hard aspects that accompany life together with cancer and the couple “longs to be more carefree.”

“The ease of life is different, just the total abandonment, being able to do whatever you want anytime.” Most of “our time together has been with me having a pretty serious disease.” There is always this “life threatening disease hanging over us and the treatments that are involved and thinking about dying.” There is no certainty that “if we plan to do something on a weekend we can do it. We have to wait and see how I am going to feel.” “It is hard. Right now my energy is very good, but for many of these years I haven’t been able to participate in the housework, in routine errands.” Brynne also “mourns the loss of my sexuality,” due to her decreased “sex drive” and because “the tissues are so thin and dry.” “It is those kinds of things, where you look at losing chunks of the life or of your body that you loved, that is hard.” Brynne has struggled with the physical aspects of what she can and cannot do and is frightened by losing physical capacity. “That has been hard on us. Having this disease involves making sure that your relationship doesn’t become one of patient and caregiver.” Brynne and her partner work at keeping their “relationship as balanced and equal as possible.” The couple finds that “cancer counselors are really good” for assisting them to deal with issues that arise

and for facilitating open and honest communication especially, on the really hard days. “I have this gift of not ever being afraid of telling” her partner how she feels.

Living longer with terminal cancer has given Brynne time to explore her spirituality. Previously she knew that “I had no use for organized religion and I knew, I believed that there was something more. I started meditating the minute I was diagnosed.” Meditation allows Brynne to be “still.” And, “the more time I can spend being still, the more I can experience things that are out of our realm of experience. The universe opens up to us when we are still and listen.” Brynne has come to believe in a universal, transcendent benign loving energy. The longer Brynne practices meditation, the greater is her sense of that energy, the “peace and a sense of connectedness to the universe” which feels “really magical.”

In that frame of mind, it’s easier for Brynne to “have the sense that I have lots of years left.” Yet, along the journey the coaster rolls in another direction where “I have a more narrow sense” of either how long there is left to live or if I want to live under certain conditions. It’s an ongoing assessment of her quality of life, “as you have this disease longer, [you] redefine what is acceptable.” She acknowledges that the details will probably change, “things that I think are essential to quality of life right now may not be essential in a year.” The essentials for Brynne this day are “love, joy, tasting things and [having] really good visual access” to see things such as “beautiful flowers.” Brynne understands that a time may come when she will gauge her quality of life as too deficient. Then she will have to confront making the decision whether to continue with all her anti-cancer, immune building endeavors or not. Brynne acknowledges that “we are all terminal; we are all going to die.” She is afraid “not of dying” but “scared of the treatments, of what’s next,” and what she must endure to stay alive. The cycle of chemo working and then not working builds and “pretty soon either your body

can't handle the chemo anymore because it is depleted or you just don't want to do it anymore or there aren't anymore treatment options available." When "that path just sort of rears its head," "I get scared," and she thinks about stopping treatments. Brynne wants "to enjoy [the] last days or months at home." She has "gone through those kinds of times" when cancer "drug protocols were hard" feeling that "this is just too much" that "everything was too hard." Those are the times in which Brynne started to think "I don't want to live like this." "It doesn't feel like a good quality of life." "It's not that I am sicker. It's just that I don't feel any joy." "I get tired of the struggle, the worry about things and working on things." "I cry, I don't want to do it anymore." At those moments, Brynne wonders, "Is this it? Do I really have to make this decision? I know I am capable of making a decision of *this is it, this is the time. I want to let go now.*" Then the hard things, the hard times pass and "things work, you feel better." Her view changes. "As sad as I feel sometimes and as frustrated as I get or as tired of it all," "I still have such good times that it is not a question for me right now of letting go." "Right now I am starting a new drug that is making me feel good and it is working so I am very optimistic." "When and if it stops working I'll get a little frightened again and get a little worried." This is the journey that winds and twists around. And for right now, "it feels good to remember that life is joyous." The "magic in just loving everything," connecting with the universe is what is "meaningful to me."

At this renewed juncture with an "average of 4 to 5 hours each day, some days more, some days less" focused on conventional and/or complimentary cancer care, "it's life on bad drugs but, it's not as bad as I thought it would be." Certainly, "I think there are things worse than cancer...other diseases...that really interfere with your quality of life." Brynne's experience is not as bad as what she previously witnessed with other family members who died



from cancer. Her goal becomes to “outlive” her mother of 85 years, survive a longer time than did her father who died of cancer at age 72 and to pass on to others that “people live who have metastatic breast cancer.” Brynne wants others to know that from her experience that “you can have a really good life with Stage IV cancer for however long you live.” “You don’t have to be cancer free necessarily. There is a place where you have stable disease where you feel really good. There is quality of life.”

Pertinent to quality of life for Brynne is recognizing that “choosing is part of the journey.” We haven’t chosen these diseases but it is what we have.” Choosing therefore is to “take control” by being “actively involved in your treatment plan, with as wide of circle of people you can get.” “I believe I have some control. It is perhaps an illusion of control. But I have some responsibility, some ability to participate in my treatment and my health.” Choosing may be about tending to the emotional plane and making a decision that will not cause her to “lose hair” again. Losing hair for Brynne is “depressing because it was something about me that I always liked. ... I know I will never have all those curls back.” It was how she defined herself and crucial to her self-image. “You’re going through this treatment that makes you feel really bad, that makes you look really drawn and sometimes bloated and sometimes just dull so it is nice that you can at least walk out and have your hair on your head so that you don’t look so different so you don’t look so bad.” “I look at it as this is a totally vain, stupid thing, but it isn’t. It is how I feel, and I have learned to just validate my feelings. [If] I can take a drug that doesn’t make me lose my hair, [if] it is going to work as well as one that does, then I will chose that one. If I can take something that is oral that allows me to travel, then I’m choosing that.”

Brynne also chooses self care by “talking to her cancer” and “talking to her liver” in addition to her meditation practice. Brynne stays “very attentive.” “I can feel my cancer when

it grows.” “I can feel it push on my colon, feel it push against my lung.” “I can’t feel it now because it is calming down.” Other crucial choices embrace complementary care with naturopaths, a chiropractor, mental health therapists, and other healers who utilize acupuncture, Chinese Herbs and supplements, IV vitamin and mineral therapy, detoxification, body awareness, and emotional release. Brynne experiences complementary care as “fun and enlightening.” “It has all worked really well together” and these “are things I should be doing whether I had cancer or not” because “it just make me feel so good.”

Brynne, in wanting to share her choices and beliefs about living longer with Stage IV cancer with other patients, struggles some though remains respectful. “I think doing the work on helping with this anger and doing chemotherapy and doing supplemental therapy is certainly improving my quality of life. I think it has increased the length of my life, because I am not dealing with new cancers and more things.” So, “I want to make choices for them [other patients with cancer metastases] that aren’t mine to make.” “I’ve done a lot of work with just letting people make their choices, just like I want to make mine.” Brynne will only go so far now as to give out references and talk of resources so that “people have information or an opportunity to do something on their own” if they desire.

Staying alive with quality of life necessitates that “I am absolutely active in the decision of my care” which endows Brynne with a strong sense of “empowerment.” It is important to her to have her oncologists’ advice so that she and her partner can then make final decisions. “This is my body, my cancer, my life.” “I don’t know the things that they know but I am learning as much as they know as fast as I can... so I make sure they talk to me then I make the decisions.” And, “I’ve been really lucky that none of them [three oncologists] want to be the main person.” Brynne was careful in her selection of oncologists and chose ones

“who listen and know how to hug” In turn, Brynne has secured the “respect” of her oncologists. “They have learned that I really know my body and have come to respect my opinions regarding treatment. Together, we are finding that smaller drug doses are better for me and the cancer.”

Brynne has encountered bountiful growth opportunities with her trek through the cancer panorama. She identifies what she has learned and the numerous changes. She’s learned to have a healthier relationship with her body. “I am heavier because of all the drugs than I ever have been in my life,” and instead of “wishing” to be back to a previous weight, is able to “think it is a good belly, good legs, good feet, good liver,” “This is how I am.” As a “long timer,” Brynne recognizes that “the liver could grow back healthy tissue” and uses this to discern “when to get concerned” and when not to worry about the rise in her tumor marker numbers. Brynne receives “little slow down messages from the universe” reminding her to change detrimental patterns. “Then when I slow down I feel great.” She is not only more attentive to her body, she is “more present with people” and to the needs of others. “I give a lot, but from a place of love, not obligation.” Brynne now does “not get angry with people much,” preferring to be “kinder.” Tending more attentively to relationships, Brynne has learned to “care much less about what people think.” Accordingly, Brynne eliminated those relationships that felt “toxic.” Brynne feels she is learning how to “deal with struggles with self-esteem or self-concepts in a more open loving and direct” manner. She steadfastly practices “opening my heart and my mind/body to the universe.” As a result, “I like how I feel in my heart and my psyche better now.” “I am much more peaceful. I feel so much more at peace with myself and my life than I ever have.”

Brynne believes that “all of life is a journey and within life we have side journeys” in which “you learn about yourself, you grow, expand... you make decisions” and these side journeys “are all life changing.” Living longer than expected with Stage IV cancer for Brynne is a “different journey.” It is a unique life changing journey that carries greater significance and “challenge” for it is also “life threatening.” “You have mets [breast cancer metastases] in your liver and think that this was the worst place it could ever end up, like a really major organ.” Yet, knowing and feeling her mortality and subsequent vulnerability makes the days feel all that more “precious.” “I wake up in the morning just immediately full of gratitude. That to me is really magical.” “I’ve had so much love and so many great times and so much enlightenment and made so many wonderful heart friends along the way that I wouldn’t have wanted to miss a day of it.”

An analysis of the horizontal statements in Brynne’s interview revealed the following central themes:

- ◇ Life and death
- ◇ Cancer as a journey
- ◇ Physical and emotional impact of living with terminal cancer
- ◇ The role of CAM
- ◇ Hope
- ◇ Significance of others
- ◇ Quality of life
- ◇ Choice

- ◇ Body self-image and self-identity
- ◇ Personal growth
- ◇ Spirituality and meaning

*Brynne's Expressive Representation: Dancing Collage*

Brynne was unable to complete her expressive representation at the time of this dissertation due to blistering and neuropathy of her hands. She had chosen to create a collage and gathered all the materials, including a 1' x 6' foot long wooden board on which she intends to construct the collage horizontally. (See Figure 4). Brynne describes the elements of her yet to be completed expressive representation:

I had this clear vision of my life and what it was like to be living with metastatic cancer so long. It was being on this ledge...something that was fairly substantial in size. And the ledge was littered, covered, filled with all the trappings of my life – the beautiful and the really challenging and the not-so-pretty, my kitties, my partner in love and joy and the ocean and shells and those things, and also with IV bottles and syringes and supplements and toilets. So I just decided to do this collage and that is where I ran into so much trouble, because my hands – I just couldn't do the scissors. I got really bad blisters from trying to do it. But here is my line, 'experience the good life.' This is my favorite bracelet for breast cancer – Mothers, Daughters, Sisters and Friends. The future, of course, is there. The journey of your dreams – this isn't necessarily the journey of my dreams, but it is the journey of my dreams now, because my dreams are a huge part of my life in a way that they never were. Let me just identify a few of these things. It is about if you were a moth, this would be your flame. Lots of things are bad dreams. There should be pictures in here, too. I can't remember – flowers, sun things, water. ...also shells. I love the beach. I love walking on the beach. ...My animal totems –they all come to me in dreams. One sort of actually a vision – I was really hurting and meditating and these wolves came to me. One of them is named k-dear which means springtime. ...It is a very power shaman totem, this green being that floats a little bit above the earth. Anyway, a wolf that stays with me almost all the time and this owl that came and nuzzled against me in a dream once. My otter and my whale that keep my heart open and protected and the wolves keep me protected and the others keep my heart open. The turtle at my back that protects my back but also keeps me grounded and slow. An owl, obviously, shows the way. ...I have my drugs ...I have syringes and supplements and all of

these things go in the pile on the ledge. My ankle bracelets, my udder cream for my hands, the anti-nausea drugs...acupuncture needles, unkempt beds, yoga mat, blood test tumor markers – things that become your life that you never even knew existed before. Interesting foods – papaya and yogurt a lot, books, slippery spots, wigs, hats, scarves and beads and my altar and wine. Then those things that are intangible that I try to pull out of the magazine – things like joy, joyful energy, love, compassion, forgiveness, pain, discomfort, anxiety, sunshine, moonlight. On this balcony there is this little tiny space where I could get away from the craziness just a little bit...a tiny foyer occasionally for stillness. I figure it is so clearly there. ...Outside of the edge on the balcony, off of the ledge or whatever it is, there is a drop but you can't quite see where it goes, but you can see around. There is a sense of lushness, of green and trees and things, but farther away and unknown, but beautiful. I have wires and colorful things to do for my hair and stickers...butterflies, candles and some really cool wires and things. Then this was going to be me. That is what the tools are for, the wire figure. I would be right here on the edge...[I would] sculpt something that is sort of freeform of me dancing on this edge right here. ...on the edge of this. I think I have been on that edge, dancing on that edge for the full six years, after the initial shock of what was happening. ...[Recently] it became so clear to me that the next step wasn't dancing on this edge, because I had always associated the leap, the fall, with death. As long as I could stay dancing on the edge, I was alive. But that is not what's going on. ... I think there is another really big step for me. I'm almost there. I am almost there. ...I would be twirling still, but my feet would be just a little off the ground– like poised in the position that is ready to fly or ready to leap. I may fly. I may drift softly to a beautiful place that I don't even know about it. I may crash and burn. And that it is all okay. ... I wasn't able to finish this. It has just been really difficult. I would like to still do it... it [creating the collage] helps me see who I am and how I feel on a different level.



recurring,” and “then it came back.” When the cancer returned, several years later, it had spread to her bones, liver, and lungs. “Then I had to go through all that hell. That was very unlucky.” Part of that hell encompasses Simone’s cancer treatment history which necessitated surgery, extensive and radical radiation, a feeding tube, hormonal therapy, and prolonged periods of chemotherapy drugs. A few years back, because of radiation side effects she “couldn’t eat” and “threw up everything” which contributed to huge “weight loss.” This combined with the inability of her body to “handle all this toxicity” of cancer treatment, caused Simone to fall into a coma in which she “almost died.” Over the past years, Simone has had to deal with many adverse and debilitating physical effects, and the emotional residue of living a long time with a life threatening disease. The “very good news” of living past expectations is that “I did, which many other people don’t get to;” “most people don’t live with metastatic disease long.” However, the good news is peppered with bad news. The “bad news is that you live, for however long, let’s say for a really long time... with this thing,” “knowing that everyone has this [cancer] come back,” “knowing that I am supposed to die,” “just looming over you.” “I feel scared.” It is living longer with trying to manage that fear, experiencing “sadness and anger about all these things that happened to me,” and “constantly” feeling “misunderstood.” Simone is trying “to fix all this [emotional] stuff because why would I want to claw my way into a long life just to feel bitter and alienated and lonely and angry.” In reflecting on living longer, Simone laughs wryly when saying, “And you get to feel these things for a really long time.” “Obviously, I still think it is worth it, but it is a mixed bag.”

Living longer, no matter the sacrifice, has great significance for Simone. Physically surviving advanced cancer treatment has not been easy, “everything I get is the worst case they have ever seen.” “I had the worst case of radiation esophagitis they had ever seen. I had the



worst neuropathy.” While taking one chemo drug “I had bleeding splits all over my hands and feet.” “It was just so painful.” “A lot of times at my house I would just crawl around.” Because of neuropathy, Simone at one time was “falling all the time” and “couldn’t do anything with her hands.” She continues to be challenged with maintaining overall muscle strength, has residual disability, neuropathy, in her hands and feet, utilizes a walking cane, and had to relinquish artistic talent that relied on her hands. Simone endures and has to navigate fatigue. For Simone “life is totally changed” and she is “not like I used to be.” “I never used to get tired. I get tired if I do too much...like walk around too much. I am exhausted...like some old lady. That is just alien to me.” And throughout all of this experience Simone adamantly declares that “there was never any point where I thought this just isn’t worth it.” “There wasn’t a single moment.” “I wouldn’t have done anything any differently.”

There isn’t a treatment that Simone would forego or a “side effect that would stop me, unless it was making me die.” “If a drug is working I’ll keep taking it. I only have so many, and since I intend to live a really, really long time, I don’t want to waste anything.” Simone has requested from her oncologist and has received additional and more aggressive chemotherapy treatments beyond that which was considered protocol or recommended. Simone asserts that her physical quality of life is not worth as much as the preciousness of staying alive. “All I care about is that I want to be alive.” “If I am not alive, how am I going to live my life? How am I going to do all these things that I like to do if I am dead?” Others have said that “Simone will just not give up,” and may “have the strongest will to live of anybody they know.” Simone admits she has bargained to stay alive. If Simone could “bargain with somebody who is actually running this show that I could give up x and then be cured” she would be willing to suffer “big, big, big, loss.” In order to reach old age, “it would be hard, but I definitely would

be willing to be a paraplegic.” “I wouldn’t even think about it.” She contemplates even becoming “quadriplegic” in trade for more years. “God, that sounds really bad, but I still think I would rather be alive.”

When others do not understand her tenacity, attributing her feelings to, perhaps, “having just finished treatment” with two years of chemotherapy, Simone describes herself as a “seething cauldron of anger.” She becomes especially angry with medical professionals when they “treat” her “as a dying person.” She reflects back on those times when non-oncologist doctors assumed all her symptoms were caused by cancer metastases, rather than understand that most often, her symptoms were reactions to cancer treatment. She experiences many doctors who act like “idiots,” without any “idea of what they do to me” with their words. “I think they must have a book of things to say to scare people.” Remembering specifically the months of vomiting preceding her coma, Simone’s experience was that doctors “didn’t really try to figure out what it was...just kept saying you must have cancer in your stomach.” When she “was literally wasting away” from the “effects of radiation,” “all the gastro docs disagreed with each other.” Simone was “the one who figured it out,” that “they had radiated that little valve at the top of my stomach and it caused the vomiting.” “If they thought I was a non-dying person, they would have worked hard to find the cause and fix it, but I was just a throwaway. They were just palliating me. How dare they?” “It makes me so angry. I have come so far. A lot of it has just been luck but I feel like they should have respected me and realized they were looking at something different.” Simone is unwavering in wanting to be treated as an individual and not lumped together “as part of this group” where she is just “treated like any other Stage IV person” who will die. She demands that “no matter how sick I am, don’t you dare treat me like I am dying.” “When I am dying I will let you know.”

Right now, death is not an option for Simone. Contrary to close calls, she believes that there isn't any evidence to conclude that she will die from this disease or has been close to dying. Simone has learned to tell herself that dying from Stage IV cancer "doesn't happen to everybody." She is resolved "that I could be the one that is different." Simone believes in "possible improbabilities" in that she "could be one of those people" who responds well to treatment and may possibly be "cured." "If it is possible, then why on earth can't I do it?" "A few others have survived long term so why not me?" "From the very beginning, I always held in my mind that even though not very many people survive, there is a very small number that do. How do we know that it is not me? How do I know I am not the one?"

Simone has been "working on my miracle" in which widespread metastases to her liver and lungs has been in "complete remission" for the last four years and the cancer in her bones, in the last three months as indicated by recent scans, are showing "no evidence of disease." She hopes that "I will live to be 65 years old. Some women laughed when I announced my goal was 65 because they don't think that is old. I reminded them that for me it is 24 years away." Simone knows that cancer could come back. She knows that "cancer could kill me." And, she loves being told that "I am in denial." "Because I know that I am not." Though, "I still need hope." "People hope for different things, like they won't be in pain or that their family won't feel too bad, my hoping is just purely about I don't want to die. It has never gone any further than that. That is the only thing I ever hope for."

Not wanting to die is also longing for some reliable source to give her the comforting news that she could beat the odds. "I would love it if some doctor," "somebody who really knew" "would say I can't guarantee this, but I think maybe you are one of the ones that is different," "maybe things could be different for me from what they have seen in the past."

“That would feel so good.” Simone viewed an “old study on the Internet” that suggested that people who survive a long time tend to continue to survive. Simone concluded from this study that “if you are doing well, you are more likely to continue to do well.” “That makes me feel so good. I love that. It gives me hope.”

Hope and comfort do not come from being aligned with spirituality for Simone. Simone’s opinion is that “either you believe or you don’t.” “I don’t.” “I never really did” have any kind of spiritual practice. People have told her that her cancer is “part of God’s big plan” to which she responds “Really? My suffering is part of a big plan? What kind of a plan is that? If this person was your wedding planner you would fire them.” “I wish I did have a faith.” Others “find it so comforting and I would love that.”

Simone wonders why others with Stage IV cancer do not share in her determination to be “just willing to do anything” especially when it comes to “sticking with drugs that are working but have bad side effects.” What Simone doesn’t understand about those “other people,” is why so many are resigned to die when diagnosed. She asks, “Where is the outrage? What about “This is bullshit!” Simone concludes that “I just don’t understand them.”

Simone also feels, in turn, that others don’t understand her. Feeling misunderstood occurs frequently at work. Simone throughout all of this time continues to work close to full time hours because she thinks that “the only thing worse than being sick is just sitting at your house all day thinking about being sick.” She is grateful to co-workers who have “been wonderful.” “They care about me” and nobody ever says anything about missing work time. However, Simone feels that the people there don’t know what to say or do, “not a single one of them.” She grows “really frustrated” when nobody understands and when they offer “dumb-ass” suggestions. Describing her attempts to explain her situation to her colleagues,

Simone “just want[s] to grab them” because “everything I say, they don’t understand. It is just like I am beating on this glass wall and the people behind it speak another language.” “I am in this world of they can’t understand me and I can’t understand them.”

She wishes there were a few more people around that understood. Living longer by “surviving this thing you weren’t supposed to survive” “makes you feel even more lonely than other people” and that “you are not like anybody else.” “I am not a normal person. I am not a breast cancer rookie, a cured survivor of early-stage breast cancer. And I am not like other metastatic women. I don’t know what I am.” “It’s hard because I don’t fit anywhere.” And, “you don’t have anybody to talk to.” There are not many support people in Simone’s life who understand or who have had a similar experience. She wishes there was a “support group just for people like me” “who had metastatic disease and are doing really super-duper great.” And Simone acknowledges that “I am always wanting more support than I have.” Her spouse is a “fabulous support” but she does not want to rely on “just one person” “because it is too much for him.” This is “why I feel lonely.” And the loneliness brings on sadness.

To meet the challenge of all these raw emotions, Simone has found that “you can sort of keep the feelings in a file cabinet, where you can still feel them sometimes.” “I am going to be sad about it sometimes” but “it’s not going to ruin the rest of my life.” Simone doesn’t want to spend the rest of her life in fear, and later feel that “I wasted my whole life being afraid.” Simone wanting desperately to hear from others that she will live a long life, recognizes that she will “have to say that for myself” and will need to “let go of expecting others to understand.” Instead, she’s “deciding” to make a choice to think that it is “okay, they don’t understand. They’ll never understand. That’s just the way it is.” Simone feels she has been “unlucky in a lot of ways,” but that she is “not going to let it ruin my life.” “I just tell

myself that” and then “I just always fall back on luck.” “I am lucky because most people wouldn’t be here years later talking about this.”

An analysis of the horizontal statements in Simone’s interview revealed the following central themes:

- ◇ Life and death
- ◇ Lucky and unlucky
- ◇ Physical and emotional impact of medical system, cancer, and treatments
- ◇ Determination and choice
- ◇ Hope
- ◇ Relationship with others
- ◇ Feelings of alienation
- ◇ Life has changes

### *Simone’s Expressive Representation: Alienation*

Simone has been unable to continue creating the charcoal renderings she used to love to draw (see Figure 5). Hand neuropathy from cancer treatments has left her with diminished fine motor abilities. She is no longer able to hold the charcoal in her hands to direct its artistic movement. As an expressive representation of living past her expiration date Simone chose to create a poster board depicting four distinct groupings of people and what they speak (see

Figure 6). This dialogue is displayed in typewritten quotes displayed above and along side the figures. The text of those statements can be found in Appendix E. Simone's described this expressive representation:

This poster is supposed to illustrate how alienated I feel. ...here are the breast cancer rookies. ...these are the normal people who have never had cancer and don't know anybody that has had cancer. Here is the metastatic people. Anyway, all of these things that I wrote are either things I heard or pretty darn close. ... Here is me. I think all these things and a bunch of other stuff, and then there are these other people that I deal with and this is what I hear. I feel alienated. That's always one of the very chief emotions. ...I get really angry here. I thought of other things to say after I already made these, but I thought oh, I don't think I can fit them in. ...At the time I thought about it [making this poster], it was pretty therapeutic. I was thinking it really shows just how alienated I feel from other people, just getting these things down that were rattling in my head, getting them down on paper.



Figure 5. Simone Charcoal Drawing

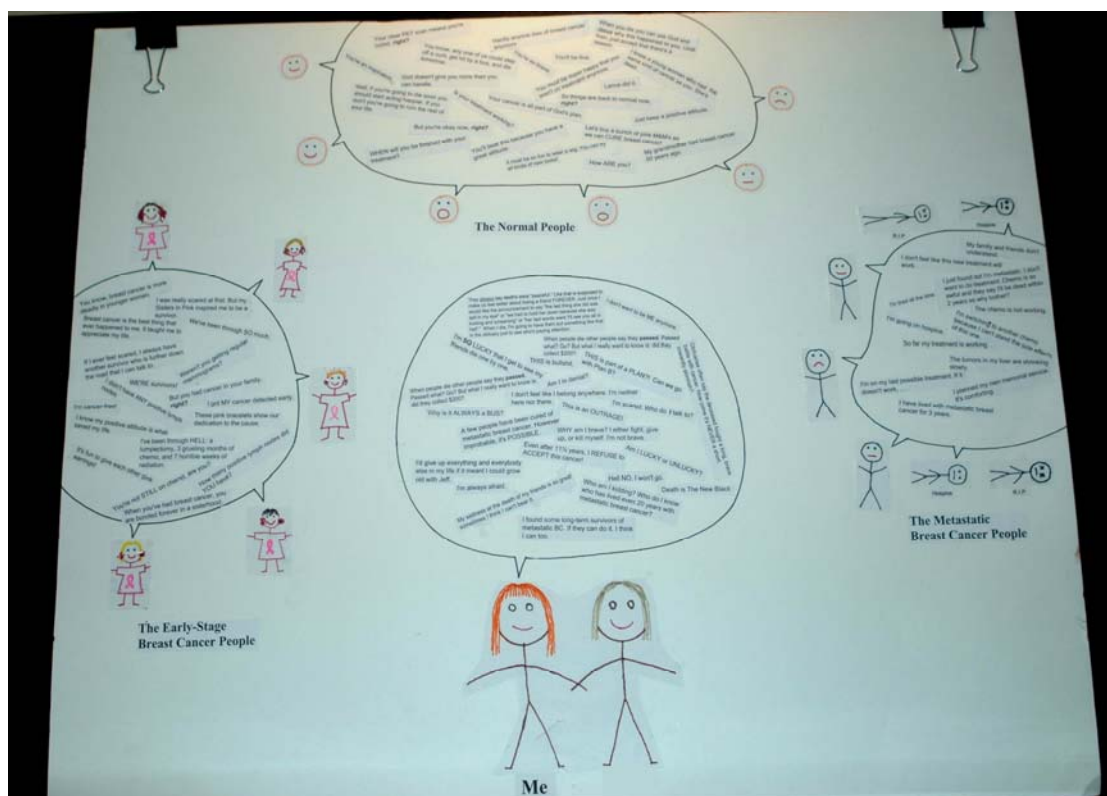


Figure 6. Simone Expressive Representation

*Christine's Individual Textural Description: It just so hard*

Although “it was a surprise in some ways” for Christine to live past her expiration date, still living with Stage IV cancer is a dichotomous experience wrought with a “mixture of emotions and feelings.” The experience runs “that gamut of its great in one aspect, but it is hard.” “My experience has been a roller coaster.” On the peak side of the ride, Christine “wasn’t supposed to be here now, but I am.” The cancer is still only in her bones and has not yet spread to any organ or tissue. This was a different outcome than what the doctors had



expected, which was that wider spread metastases was “probably going to happen sooner.” They told her not to plan on a long life. Christine believes that living past the time expected is the outcome of “new things happening” and that “expectations have changed over the last seven years.” “I am actually meeting people who have it in their organs and soft tissue and brains and are living longer.” “It’s this funny thing that I am not going to die from this yet.” However, as the coaster dips, Christine’s experience is “like constantly” “trying to walk a tightrope” with feeling “lucky” to be “alive,” to be living longer, and to “still” be “doing it with a good quality of life,” while “the other part of me” is “angry and frustrated that I have to deal with this.” While nobody has any guarantees” and “I recognize that, on the other hand, part of me says I am almost more upset that, oh, gee, but I have to have this thrown in my face.”

“I can say not a day goes by that I don’t think about the fact that I have Stage IV cancer and will probably die of this disease.” Christine’s doctors have told her that they are “never going to cure you but we can really start to work on this like a chronic illness.” With treating metastatic cancer as “a chronic illness,” Christine comprehends that with a chronic illness “you can live with it for a long time if you change behaviors.” But Christine “can’t quite change behaviors or do whatever with” her cancer to affect its course. “So it is a chronic illness but it is not a chronic illness. It is a chronic illness with death right there.” And that’s where “doctors” “don’t know what to do with this.” “Doctors don’t know what to tell you. It could be three years or three months.” Christine is “living longer and that’s great, but it is all this huge unknown.” For Christine, “who is somebody who likes to be in control this is very hard.” “There’s a part of me that I buy it, that I am lucky that I am able to” live past expectation and live longer, “but I don’t know what’s around the corner.” Seven years ago, Christine thinking she would not live long enough, “figured there were things I didn’t have to mess with” like

“worry about retirement.” Only “now I do.” Christine has to consider preserving things and jokes that now she has “to go back to the dentist and start flossing her teeth again.” For Christine it “is a mixed bag where I am almost wishing I knew how long I had” because then she and her husband would know if retirement was even going to happen. There are the times when Christine wishes somebody could tell her if “you’ve got two years, you’ve got five years, you’ve got ten years.” “If it was two years, then I would do this with my life. If it was ten years I’ve got to do something else.” Christine wants to discern how much time she has so she can decide “how to manage my time.” Christine wants to know “do we do things sooner” or “do we do things later.” Ultimately, she just tries to “enjoy the day.” “When people say” to Christine “oh gosh, you are doing so well with this,” she thinks, “What else am I going to do?” “What are the options there?” “Am I going to sit with my head in the sand?” “I am going to try and live the best life I can.” She has learned to just accept life with cancer as it is, “but it does, at times get hard.”

What is hard is dealing with the unknown and not being able to foresee what her quality of life will be. “It is that thing where you constantly are, gosh, you are so happy to be alive. You are fighting this and you are doing whatever.” “Then every time I feel better and I do some stuff, something pulls me back.” “I feel like someone is coming out there and grabbing me and pulling me back. It is like, ha, ha, ha, you thought you were going to get out of there, and no, you are not.” For Christine it feels like “quick sand” in that “I just know I am never going to get out of it. That is really hard. If I knew that, okay, if I do all this [treatment],” “I can get it [the cancer] beyond me.” Then “fine... I can do it.” “But then no matter what I do, no matter how hard I try, no matter how everything goes, what is the end

result. I am going to die. I am just going to die.” And “sometimes you just have to say what is this all for? I don’t know.”

In the cancer world “while there are people who say, oh, gee, my life has changed and it is so much better. I look at things differently – there is part of that that very definitely is true, but there is also part of it where I just want to gag on that, and say, oh, give me a break.” Brynne does not believe “in that hokey thing of looking at life differently.” “She is “sick of being a cancer patient.” Christine is tired of having to deal with the ongoing series of challenges of new tumors, treatment protocols, and the side effects, all of which have “become so much a part of my life.” Christine has had “some amazingly, phenomenal wonderful times” in challenging herself, “putting myself out there” “and doing some things and looking at things I might not have done [before] that have brought me some amazing happiness and joy.” Some of those wonderful things included going to Europe with friends, moving into her dream home, and establishing her own business and learning to set boundaries with clients. “Yet on the other hand there have been some times where I am up at 3:00 in the morning and I am talking to my dog.” It’s in her dog’s tilted gaze, that empathic “do you need a dog look” that provides Christine some solace in talking. The look “is the best thing in the world.” It allows Christine to talk with her animal companion about what she dares not tell others in her family. Yet, if her dog “ever learns to talk I am so hosed.” When Christine talks with her dog in the pre-dawn hours she gets “whiny,” “cries” and feels she is “having a bad attitude.” It is the occasion when she thinks of the “nasty people” she knows in high positions and where they abuse power; she wants them to have Stage IV cancer. “Why doesn’t he have cancer? Wouldn’t that save the world from a lot of things?” Christine feels that “it’s not fair” that she has to go through all of this. Christine at these times feels “out of control with this and is just

so frustrated.” When it becomes overwhelming, Christine asks herself “why me,” “why do I have to do this with my life.” “Why do I have to spend this time? Why do I have to focus all this time and energy on this when there are so many other things I would love to be doing?” She feels that in some ways that dealing with ongoing cancer is “just such a waste of my time.” Living longer with Stage IV cancer becomes “this all-consuming thing of my life” in which “I’d much rather not be dealing with this.”

There is a huge range of emotions “because on one aspect you are supposed to feel phenomenally lucky.” It’s a situation where Christine grasps that she is supposed to feel: “Isn’t this great.” “This is so wonderful” that “I may be able to try this new clinical trial,” a new drug that would keep her alive longer. “Aren’t I lucky?” But what follows is that Christine does not feel all that lucky because “it is not even a normal week for me unless I have at least three medical appointments.” “In one aspect I think it is great that I have been learning more, looking more, and able to deal with this. On the other hand, part of me of, oh, god, just doesn’t want to.” Christine just doesn’t want to do it again. It gets to “that point where you are really frustrated with it, when you are sick of it, when you say I don’t want to do another treatment. I don’t believe I’ve got to go through this again.” And “you feel extremely guilty” because “I am supposed to be so happy to be alive.” “Who the hell am I to have those feelings of that, where this isn’t lucky.” “The audacity of me to feel, I just don’t want to do it again.” “How can I say that?” “Who am I to bitch and complain about this.” “I’ve got all this stuff but I am alive.” And yet “you feel like you can’t do this.” “I feel like it is just sucking me dry.” Christine is mentally and physically “sapped.” “Right now, I just feel like I’m so tired. I am so tired of living” as “a cancer patient.” It has “taken everything out of me.” “It is just so hard.” “It is hard living with it.”

“It is just so hard to just keep going with it.” It’s been seven years now that Christine has been managing breast cancer metastases to the bone. In the year of her re-diagnosis with metastases, she “had the year from hell with five surgeries, chemotherapy and radiation and back on chemotherapy,” off and then back on again. In the years that followed, Christine’s prognosis “would get me between nine and twelve months on a drug.” “Then the cancer would find its way around it.” “I’d get another couple of spots and do either chemotherapy or radiation for that series and then switch to another drug.” She went for six years with everything just in the left chest wall. Although, three years ago she had a “simple trip in a parking lot,” fell and shattered her right femur in three places. Instead of normal bruising, the break was a result of the “bone drug I am taking [which] is making my bones stronger but also makes it more brittle.” Christine lives with how “I can crack a rib now and break a rib by coughing, turning funny, by doing something because I’ve had radiation four times in the left chest wall, to stave off another local reoccurrence.” She lives her life “where I’ve got ribs that will never heal.” And “all of a sudden now it [cancer] is down in my femur.” Christine recently had surgery on her left leg “to put in a rod to stabilize it before radiation.” In surgery because the cancer had eaten the bone, her leg broke. “Now I’ve broken both legs and have to go through that.” As Christine continues to have swelling in her leg, both she and her doctor suspect that this leg, like her ribs, “will never fully heal.” And her last scan showed three new spots, “two in my pelvis and one in my spine.” “So all of a sudden it is spreading;” “it is moving.” For “the first couple of times it is like okay, you are doing it, you are going on.” She accepts that she has another tumor and will have to go through treatment again. Christine also manages by using “alternative medicine and worked with a naturopathic physician. I do acupuncture. I do things to try to keep my immune system as strong as

possible.” “But there are times when, oh, god, how many times do I have to do this.”

Christine has now run the gamut of the “aromatase inhibitors;” the current drug she is taking is no longer working “so I’ll definitely be back on chemotherapy in a couple of months.” Christine “knows that I’ll be on and off chemotherapy for the rest of my life.” Christine’s treatments have “kicked me into menopause” and she is “having an awful time with that.” She suffers from the side effects of lymphedema and insomnia which keeps her “up and down all night.” Christine also has had to learn to live with a certain amount of pain and reluctantly relies “on pain meds most of the time.” Christine’s response to all of this is “oh, gee, isn’t this fun. Just let me deal with the cancer.” “Isn’t the cancer enough, then all these other things [are] affecting your life.” “With each step along the way...it gets harder and harder.”

Christine recognizes that all of the treatments she has had are all “choices I have made;” they are “life choices” which includes deciding that “because of all the cancer and stuff it just wasn’t going to work for us to have kids.” “On the other hand,” Christine believes she and her husband are good aunts and uncles. Her goal was to “live long enough that she [her niece] would remember me.” “I’ve achieved that.” “Do I let myself go to the point might I see her graduate high school? I don’t know.” Christine “isn’t somebody with kids” who has “goals like that.” She is someone who wants to plan for her time and has “up to this point,” “been able to make the choices I want to make, live the life I’ve wanted to live, do the things I’ve wanted to do without it drastically effecting me.” Now she feels the cancer is “taking more of an emphasis on my life.”

The tumors and bone brittleness are taking their toll and affecting Christine’s quality of life, specifically her ability to work. Up until now, Christine has “been able to continue working through the whole thing.” Recently, at work, she was “doing what I normally do and

had a hard time doing it.” “Last month when I came home [I] was in bad shape.” “I am on my feet for my job.” “I am moving and doing things and all of a sudden now it is beginning to affect that,” Consequently, Christine is talking now about whether she is going to quit work. For now, she has “pulled back” and delegated more of her tasks. Contemplating the limiting effects of her current physical situation “is the stuff that is hard” because it is “beginning to affect my quality of life.” Christine is not sure that she wants to stop working. “Even if I stopped work, I would just be pulling back on my side of things. There would still be things I would be doing.” Christine would still be inclined to help with “managing” the less physical aspects related to her businesses. Christine feels cutting back on work “might be good.” She reflects on hearing how an acquaintance who quit work could “get 10 to 12 hours of sleep a night and then wakes up in the morning, takes her time, and then goes to the gym.” And since Christine can now only walk a few blocks and not the “40 minutes” she did previously for exercise, she wants to “commit to getting to the pool three or four times a week.” Then “guilt” surfaces and both she and exercise get placed “always at the bottom of the list” in terms of Christine’s priorities. Christine thinks she can’t take more time and “put myself first” because in terms of who can slacken she places herself last. “On the other hand,” she feels “very lucky that I love what I do” and concedes that “one of the reasons I have continued to work and do things [is] to keep myself on an even keel,” to “balance out” having cancer and living with its impact. In mulling over whether to quit, “there is the part of me that says, oh, but then cancer is going to become even more a part of my life” where she will have to live around cancer instead of incorporating into her life. Christine does not want cancer to define how she lives. Christine believes if she stops working “then it is almost saying, like alright I am giving in,” that cancer “is winning and in control.” So even though part of her is “envious” of what some

of the other women who quit their jobs do, “the other part says ahhhh, I am too afraid of going there.”

Christine’s fear is that the physical impairment from the cancer will soon force her to “really make changes.” Accepting those changes for Christine signifies that this “is the beginning of the end,” “the end of my life.” What and how the ending will be “is the really scary part that I have been lucky that I haven’t had to go there.” When she was first re-diagnosed, she “pulled out the book” that “said metastatic disease, 18-24 months” and promptly put the book “under the bed,” declaring “don’t want to read that one.” She felt at that time that “I am not at that place yet. This isn’t going to kill me.” Christine has a “file in my computer of my funeral and all the things I want because I don’t trust anybody else to do it” “exactly” as “I want it.” Occasionally, she updates the file with a letter to a loved one or a piece of music she would like to have included in her memorial service. But that is as far as Christine has gone. She has not wanted to think about the details of dying because it was “too frightening” and since she has not “gotten to that point of death,” “why push it.” Christine has been “just kind of living my life” with “how am I going to live today, get through this and go from there.” Christine has learned how to live with cancer and to not to let the cancer overwhelm her. “I’ve accepted that I have Stage IV cancer. I have been living with it all these years, so okay, I can do this.” Christine is “expecting that I will die of this disease, but it hasn’t been right there.” But now “all of a sudden cancer has taken a bigger role. Instead of being the appetizer, it is moving to the main course. It is like, wait a second, hold on, no, no, no. It is like I’ve accepted you to this point, but I don’t want it to go further.” “Do not tell me that I can’t walk. I can’t do that. I am just not ready to accept it yet.” Christine is not yet ready to use a “wheel chair.” “I am still not at the point of turning around and saying, okay, this is how I



have to change my life, this is how I have to incorporate it” because she still is hoping for “a solution.” Christine admits that if she can find no resolve to her decreased physical capacities, “if I am really honest with myself, it is probably going to happen at some time,” “then I will have to look at that and deal with it.” “But that is the scary part.”

In the last six months, Christine has had to start another round of chemotherapy and experiences increased difficulty of walking. She has decided to use a scooter chair on occasion for long walks or for when she will need to be on her feet for many hours. Getting around became more important than whether or not she used a physical aid. Christine is glad to be mobile. “This last year was harder for me, but still functional. I’ve had to make changes in my life, but I am not bedridden.” Although she continues to work, she has re-evaluated her priorities once again. Christine now looks at taking larger chunks of time off work to explore her creativity, visit with friends, travel and examine what is important to her. “I’ve reprioritized things...giving myself time to do those things that I might enjoy, which might be very simple, but a little more creative and fun than in the past when I am just busy and going.” And the idea of her cancer progressing is still hard and scary.

Getting progressively worse is both the scary part and “the part that is harder because it just keeps going on.” It so “drains you with everything” “that Christine is beginning to consider: “How long do you do this?” When Christine was recently hospitalized for this last leg surgery, it was a period of time in which she thought about the quality of her life. Christine thought that even though she was not yet there physically, she understood why someone might want to end their life sooner. “I can so understand for the first time the people who just say, I’m done. I just can’t do it anymore.” “I am so sick of living my life like this. I just get sick of going on.” “There are certain times when I can say, okay, I just want it to be over.” “Just do

it or not” because Christine does not know when the next time that her scans will reveal “another bone met” or when a day comes that her metastases will “turn around and it will be in my liver or lung or brain.” She “knows that that’s out there.” And “that is the hard part that you don’t say to anybody else, no matter what.” “Because I don’t think anybody would get it at all.”

Christine can be open with both her siblings and is particularly “close” to the youngest sibling “who is willing to listen” and with whom she “can talk to pretty honestly.” “But if I ever said [that] I’ve just had it, I’m giving up, she would be oh, no, no, no, you can’t do that.” Christine can understand her sentiments and also realizes that there is really no one in her family with whom she could express how tired she is of all of this. “My mother, who is in such denial about all of this, can’t go there.” Christine tried for six months to inform her mother of the seriousness of her cancer. Her mother tells her, “Of course you are going to be fine,” “you are going to do this like you did everything else,” “it’s going to be okay.” Christine acknowledges that the thought of a parent losing a child is extremely tough. “She [mother] just doesn’t want to go there.” “So there is a little bit of walking on eggshells with her.” Christine’s husband is a “combination of in one aspect very protective,” and takes charge and lets her know “this is what you need to do.” “Yet on the other hand, I know that when I am feeling better, I’m back to myself,” “he is very happy because then it seems like I am okay.” And everything goes back to how it was where “life doesn’t stop, things don’t stop, you just keep going with it.”

Christine knows others diagnosed with Stage IV cancer “who are going through it” whom she can talk to “who understand and can say ‘Yes, I’m with you. I [too] have had it.’” The “benefit” of sharing with these individuals is extremely valuable for Christine. Amongst

those people, she has seen a range of “ones who have fought all the way to the end and just never say no, and keep going. And other people who said, ‘okay, this is it. This is as much as I can do.’” For Christine it is also “this mixed bag” of seeing somebody in hospice or somebody who has died from “this awful disease that is killing people” and then having to “put on this face to the world” where “I am supposed to be so happy to be alive.” It is a mixed bag for Christine to have become connected with others with advanced cancer and to have “lost some good friends to it.” But by connecting with others in similar circumstances and talking in therapy, Christine is realizing that she is not totally “alone,” and that there is “a safe refuge” to “talk about those things” “whether I choose to talk or not.” She feels comforted that “they are there” on the “roller coaster” with her. Seven years ago, in the year of her re-diagnosis, Christine could hardly find someone with metastatic cancer. “So the fact that there are people out there, [that] there are other resources, [and] that more things are being done about it,” “I am hoping that [with] the next generation of people who have to go through this” that “it is not just an uncharted territory.”

It has not always been easy for Christine to admit to her feelings about all of this. Previously, she “just didn’t want to go to [those] places.” Now, acknowledging her emotions is “a huge thing for me. I am not from an emotional family. We don’t do it.” Christine worries about the emotional impact of all this has on her family members and friends. Embedded in Christine’s memory is the intimacy shared when “at the beginning of this, my husband turned around to me and said, ‘I just never expected not to grow old with you.’ You know, that just broke my heart.” Christine’s heart breaks because she can fathom that her dying “is not fair to do to him.” “That’s so hard for me in terms of my family and friends and people who have been there with me.” Her family and friends have been there for her since the initial diagnosis

of breast cancer in the early nineties, through the years in between, and through these seven years during her re-occurrence of Stage IV cancer. Christine's friends want to "help and do whatever" and "everyone rallies around and this is great." "But it is like how many times can I ask them to do this." Christine, unlike her husband, needs a whole bunch of people around her and is eager when "somebody calls me up and says let's go out for lunch." "I can manage that" whenever, "because I am a very social animal and enjoy that and enjoy those relationships." Whereas, Christine's husband "is very supportive," "he isn't somebody who talks about it" with others. She worries about how he will fare after her death because "if he was ever going through something, he says 'I have you. I don't need anybody else.'" Then Christine thinks, "oh great, if I am not here what's going to be there for you." And then she remembers, that there are a few people he could turn to, a friend and one of her siblings. Christine has also reminded those who are close to her husband that "he is somebody who doesn't like any sort of ceremony," so when Christine dies they need to understand that "he might be here" or "he might disappear" and "you guys have got to let him do whatever he does." Christine comprehends how death leaves loved ones bereft because she shares her husband's sentiment of what there is to live for. It comes in a quote from a Carol King song. A song Christine has "always loved." Christine, echoing the words of the song, has lived because "I am no longer doubtful of what I'm living for, because if I make you happy, I don't need to do more."

An analysis of the horizontal statements in Christine's interview revealed the following central themes:

- ◇ Life and death

- ◇ Range of the physical and emotional effects of ongoing cancer
- ◇ Uncertainty and management of time
- ◇ Importance of work
- ◇ Choice
- ◇ Changes over time
- ◇ Relationship with others
- ◇ Meaning and meaninglessness

*Christine's Expressive Representation: The Wedding*

Christine's expressive representation is a montage of photographs she took of some of the pieces she created in planning a wedding for a dear friend's daughter. (see Figure 7) How this project represents her experience of living longer than expected with Stage IV cancer is best described in her own words:

It is taking what I have learned in the last seven years as a cancer patient. I wouldn't have gone down there for three days in the middle of work. It would be more I've got to work, But that is where it has changed. I've reprioritized things. Helping these friends is more important than work which wouldn't have happened in the past. That is where cancer plays in to it. ... This is what is really important in my life. ...Planning this wedding gives me an extreme amount of joy since I've known her [the bride] since she was 8 years old. I am not going to be able to do this for my own child. [tearful] I will never have my own children [because of cancer]. So this is a special treat out of the blackness, a bonus to share and be a part of this tremendous joy. I am lucky to be alive to witness and participate in this wedding. Planning the wedding is being creative ... possibility...beginnings. ...I thought it took my creative skills and it was thinking a little outside of the box ...trying to incorporate what was important to them for this day and yet putting a little more fun with it, a little bit of flair, doing things that would be interesting



Figure 7. Christine Expressive Representation

*Composite Textural Description: Emergent Themes*

The composite textural description links together the essential elements of all of the co-researchers' individual textural descriptions. This composite textural description was developed from analyzing each co-researcher's individual textural description for those common themes that represent the various dimensions of the phenomenon. It is not a complete listing of all the invariant constituents that have been identified for the five co-researchers, rather this next step in the phenomenological reduction results in a composite that represents the most core elements of the lived experience that emerged across all the interviews. No single core theme captures the complexity of the five co-researchers' lived experience. Several interrelated and overlapping themes emerged from the data and any one emergent theme must be considered in terms of the entirety. From the data, five core composite themes surfaced: awareness of mortality; living on a roller coaster; feeling different from others; interaction with medical systems and treatment protocols; cancer invades and changes how you live and re-view life. Each co-researcher either explicitly or implicitly spoke of these five composite themes, although there were variations in the way each encountered these issues. Each composite core theme encompasses several of the individual themes that have been previously delineated in the individual textural descriptions. Awareness of mortality addresses the individual themes of life and death, preparing to die, management of time and uncertainty in not dying with ongoing disease or NED, and the threat of death that still looms for each of the co-researchers. Living on a roller coaster encompasses the individual themes that pertain to the range of affects cancer and treatment has on their quality of life, persistence of change, and the duality of feeling lucky and unlucky. Feeling different from others relates to the individual themes of the co-researchers' relationship to others and their feelings of

separateness, alienation, loneliness, and/or guilt. Interaction with medical systems and treatment protocols encompass the individual themes of Western medicine, CAM, the doctor-patient relationship, and the all consuming nature of the physical and mental impact and toll of ongoing treatment. The composite core theme of cancer invades and changes how you live and re-view life contains the individual themes of how the co-researchers live while dying with cancer: changes in lifestyle, self-identity, relationship to work, significance of choice, individual beliefs and values, spirituality, and meaning.

In the following section, the composite core themes are elaborated upon and substantiated either with summarizing previously described examples in the individual textural descriptions or with additional quotes from the co-researchers' transcribed interviews. This composite does not offer every statement made by a co-researcher related to a core theme; instead it weaves together representative instances and quotes to portray the central and most often cited thoughts and expressions of all of the co-researchers. An outline of the composite core themes and key elements can be found in Table 2.



Table 2. Outline of Core Composite Themes and Key Elements

Awareness of Mortality	Living on a Roller Coaster	Feeling Different from Others	Interaction with Medical Systems and Treatment Protocols	Cancer Invades & Changes How You Live and Re-view Life
Initial reaction to diagnosis <ul style="list-style-type: none"><li>- emotional</li><li>- sense of urgency</li><li>- behavior / actions</li></ul> Preparation in anticipation of death (assimilate) <ul style="list-style-type: none"><li>- plan</li><li>- clean out belongings</li><li>- continue treatment</li></ul> Live past the expectation <ul style="list-style-type: none"><li>- paradigm shift</li><li>-chronic</li><li>- looming threat of death</li></ul> Ongoing orientation to death (accommodate) <ul style="list-style-type: none"><li>- not in denial</li><li>- possibility versus probability</li><li>- natural / unnatural</li><li>- after-life</li></ul>	Tumors <ul style="list-style-type: none"><li>- remission / reoccur / progress (uncertainty)</li></ul> Chemo cycle <ul style="list-style-type: none"><li>- effective / stops working / new chemo</li></ul> Unlucky / luckyExtremes of good days / bad days <ul style="list-style-type: none"><li>- alive / active / hope</li></ul> versus <ul style="list-style-type: none"><li>- feeling sick / is this the beginning of the end? / when is enough, enough?</li></ul> (quality of life)	Different from non-survivors <ul style="list-style-type: none"><li>- not understood</li><li>- media myths</li><li>- treated differently</li></ul> Different from early stage cancer survivors <ul style="list-style-type: none"><li>- they can get on with their life</li></ul> Different from others with metastases <ul style="list-style-type: none"><li>- see others as more ill</li><li>- more knowledgeable</li></ul> Feelings of <ul style="list-style-type: none"><li>- guilt</li><li>- alienation</li><li>- invalidated</li><li>- loneliness</li></ul> Yearn for / establish connection	Treatment side effects <ul style="list-style-type: none"><li>- physical</li><li>- mental</li></ul> Doctor-patient relationshipPatient-medical systems <ul style="list-style-type: none"><li>- Western medicine</li><li>- CAM</li></ul> Cancer care all consuming	Cancer is biologically and psychosocially hard <ul style="list-style-type: none"><li>- not a gift / gifts in it</li></ul> Fear <ul style="list-style-type: none"><li>- dying process</li><li>- wasting time</li><li>- poor quality of life</li><li>- addiction</li><li>- being a burden</li></ul> Employment vs hard work of coping <ul style="list-style-type: none"><li>- loss of employment</li><li>- loss of identity</li><li>- continued employment different</li></ul> Psychological development <ul style="list-style-type: none"><li>- choice / responsibility</li><li>- values / beliefs / strategies</li></ul> Spirituality without religion <ul style="list-style-type: none"><li>- connection</li><li>- openness</li><li>- meaning</li><li>- no faith</li></ul>

The following excerpt is the composite textural description of the co-researchers' experience of living past one's expiration date and still living with Stage IV cancer.

### *Awareness of Mortality*

Awareness of mortality for the co-researchers in this study was illuminated in their descriptions of their initial emotional reactions to a terminal diagnosis, their initial and ongoing preparation for the end of life, their readjustments in managing their awareness of approaching death when medical conditions shift, and their current varied beliefs and values about death. A terminal diagnosis of cancer metastases immediately catapulted the co-researchers in this study into a potent awareness of mortality. Their initial reactions to diagnosis moved up and down the continuum from shock, overwhelm, fear, and sadness to thinking about the prognosis as the next task to tackle. All five of the women described fear of their death and/or the cancerous road that lead to death. All of the co-researchers searched for other cancer survivors with metastases with whom to share their plight and garner hope. For four of the women, their reaction to the current diagnosis was in part, based on a previous history with breast cancer that was diagnosed at an earlier stage and treated several years before. Only Jo was diagnosed from the start with Stage IV cancer. After receiving the diagnosis, awareness of mortality prompted all five women to investigate what was known about their disease and they began a search for what were the possibilities of staying alive and how much time they would have left. Pearl, Christine, Brynne, Simone, and Jo researched the Internet for information on the mean survival time. Jo described the fear most of the co-researchers encountered from this research: "Everything that I read described metastatic disease – specifically breast cancer metastases – that it just comes back, even if you get to a state where you are in remission. It

was really scary.” Simone, Christine and Brynne described the common element of surprise with re-occurrence and overwhelm:

**Christine:**

I really thought, you know, I had my two year mark and I hit my five year mark, and I thought okay, that’s it. I didn’t do anything and it was seven years later, and then all of a sudden, surprise. ...and with reading through everything you kind of get overwhelmed.

**Simone:**

It was a long time, almost six and a half years. I did the five years of tamoxifen ...then less than a year and a half later, after I stopped the tamoxifen, Boom, it was really bad. It was everywhere. I just developed this sinister dry cough, so I went in there and they just on a simple x-ray, the doctor was like I am really, really sure. Anyway, that is when I found out I had it in my lungs, and then they tested my liver and I had it there. Then they tested my bones and I had it there. They tested my brain and I didn’t have it there. I was like, people thought I was insane because I was just running around, I don’t have it in my brain, yeah, whoo hoo, whoo hoo! I had it in these three places. It seemed like such a big thing.

**Brynne:**

I went eight years until the second cancer. I found the lump myself. I remember the cold sweats because I knew exactly what it was. So that was like a real kick in the shins. This is really serious now. Infiltrating cancer, but the nodes were negative and everything. I don’t even think I took a year. I think it was shorter the second time. I realized I had recovered, it was eight years, it was fine, it is going to be okay. So two years later I got, what I consider, the sledgehammer from the universe. ...I remember the day – I remember getting the call from the doctor. I was in Miami and he was in LA. I wasn’t even going to go see the oncologist because I had had a lumpectomy two years before. I had done radiation. I was like a 00.2 percent or whatever to have mets, and I get this call. .... You have mets in your liver and I was thinking that that was the worst place it could ever end up, like a really major organ. There weren’t just two of them, and they were scanned in places that they couldn’t remove little pieces like for breast cancer. ...It was just being in shock. I didn’t know how to get hold of this. You learn very quickly. This is about how long you are going to live, not this is about can we cure you. ... I got on the Internet and they were talking about two to three years to live with it in your liver.

Upon learning of their diagnosis, in anticipation of death, four out of the five co-researchers underwent some preparation for the end of life. In confronting their death, four of the co-researchers made preparations to lessen feeling scared, to befriend their fate, and to gain some sense of control over how their lives would end and how they wanted to be remembered. Preparation varied with each individual and involved reading everything one could find on death and dying, creating a check off list, talking to friends and assigning them tasks for when the end nears, imagining their dying scene, planning funerals and memorial services, and/or deciding what would become of their ashes. As **Brynne** described “these are all the things you didn’t think about before” but now there is greater urgency “to make it really clear what I want to happen and who is in charge of what.” **Jo’s** preparation changed from the first few years when she volunteered to work with dying persons and their families, to exploring what happens after death, to currently volunteering with newly diagnosed cancer patients.

**Pearl’s** preparation for dying extended to her family: “This will be the first serious experience with dying and illness that my children have had. I am trying to figure out, I guess, how to parent through that. How to prepare them for an experience that really none of us know what it is, but I would like for them to have some preparation for it, since we have the time.” Her preparation also included a “cleansing in the beginning” which continues to be ongoing process of determining when would be the right time to decide what possessions to give away and to whom. Preparing for death was further embraced by Pearl as she has thought through the physiological process:

Many of my tumors are in the upper lobe of my right lung and encroaching on the bronchus. That is a really nasty place because it is not like it is down here where I could have a pound of tumor and have fluid drained every week like. So there is a

part of me that understands that there is going to be a point in time where I am going to become respiratorily compensated if I don't end up with brain or liver mets, which would be sort of an easier process...less scary. Then I see that as sort of in phases where we will still be getting treatment and we will still be aggressively working on this. Maybe I will end up on oxygen. Maybe they will end doing a trach, which is something I hate the concept of, but that would actually allow easier breathing.

And then **Pearl** fantasizes of the perfect death scene:

I would want to kind of take to my bed and do my Camille scene. That I envision as some sort of fairy fantasy where all my friends are goddesses and they all come and the harps play and my friends sing and my sister cooks meal and my children cry and then I drift off.

Whereas, **Christine's** preparation, a file in her computer, remains in the background as a plan in progress because it is too frightening to get closer to thinking about her demise especially since she doesn't yet "have to go there." **Simone** chose not to prepare in the manners described above. To ease her fear and muster hope she chose instead to find solace solely in seeking out others on line who had survived long term with cancer metastases in a major organ. "At the beginning of my metastatic journey I hooked up with a lot of people and they were hard to find. Not a lot of people but enough that it helped." More recently, Simone's preparation could be implied in her anger at those who refuse to dispel the death taboo:

They always say deaths were peaceful, like that is supposed to make us feel better about losing a friend forever. Just once I would like the announcement to say, the last thing she did was spit in my eye or we had to hold her down because she was kicking and screaming or her last words were I'll see you all in hell. When I die I am going to have them put something like that in the obituary, just to see who is paying attention. ... When people die other people say they passed. Passed what? What I really want to know is did they collect \$200. That is a cheap, sick joke. But every time I hear that I think, god, why can't we say die. We don't have to say croaked, but just die. It is a perfectly legitimate word.

Once all the co-researchers recognized that they might live longer than expected they experienced a paradigm shift. Terminality began to take on the semblance of chronicity. Having surpassed their expected expiration, all five women strongly asserted that death for them was not imminent. None of the co-researchers at the time of the interviews considered themselves to be in an active dying phase. **Pearl** stated that “I am certainly not at any life-threatening concepts ... I don’t believe that these are my last six months.” **Brynne** asserted that “Right this minute I am starting a new drug that is making me feel good and it is working so I am very optimistic. ...My reality is that I am doing really well [laughter] and my body is doing its best to heal.”

#### **Christine:**

Treatment is still working, it is contained. Doctors have said we will never cure you, but they have been treating it like a chronic illness. ...I deal with it as a chronic illness. I go back on chemotherapy or I do radiation, so I have been on and off it for seven years now. But each time, so far, that spot isn’t going to kill me. I haven’t had that one that is going to do it. Now, deep down in my gut, am I going to die of this disease? Yes. With the movement of stuff this last year, whoa, what is happening now, it is taking its next step. Every step along the way brings it a little closer, but again, I’ve been lucky. I am not there yet. ... I am kind of in this in between ... I’m here, I’m there, but I am not at **that** point.

**Simone’s** body was full of cancer when she was hospitalized from the side effects of cancer treatment in 2003 and she became comatose. Simone perceives contradictorily the impact of that experience and her current cancer treatments. For Simone those experiences are separate from the cancer that threatens her life:

During the coma, at one point I was close to death because my kidneys started failing but they managed to turn it around. But I wasn’t there to be conscious of, oh, my god, I’m close to death. At other times, even though I was probably much closer to death than I thought, I didn’t feel like I was. ...I just don’t feel close to it. ...There

isn't one single shred of evidence in my past, of anything that's happen, I have never even been close to death – other than the coma, but I mean from cancer.

**Jo** was given a prognosis of two years or less and although she is still considered to be living with Stage IV cancer, she is currently in remission from breast cancer metastases. With no evidence of disease (NED) for five years, she is far more distant in her perception of imminent death and believes she may even die from something other than cancer.

Not dwelling as close to imminent death as expected created a dilemma for the co-researchers who all expressed that they have had no role models for how to live in this unprecedented amount of time. For **Jo**, she is constantly searching for validation that what she is doing is working. For four of these women the dilemma is complicated because while they still have vitality they are simultaneously slowly and steadily receiving daily, sometimes moment to moment, reminders that they are progressing towards death. “Looming” was the word used to describe the felt sense of death’s distant presence. Looming holds life captive by the awareness of mortality in ever present thoughts about disease, physical decline and emotional distress. **Simone** described it as “the little voice that says, ‘You know everybody has this come back, okay. What are you thinking here? Like you are going to live to be 80 or something? Are you crazy?’ That is the looming. ...You live with that threat ...just always living in that...just thinking about it day and night.” For **Brynne** that sense of looming appeared when she clarified her response to thinking about death: “It hasn’t been as deep in my heart as it has been for others, but it really gets your attention all the time.” “It is like dancing on the edge of a long, narrow balcony 10 stories up – a balcony that doesn’t have a railing” and longing for the “carefree days” when “there was no life threatening disease hanging over us, no treatments” to endure. Looming for **Christine** was described as watching your own dying with

no escape routes in sight. For Pearl, Christine and Brynne, looming is knowing well from what and how they are likely to die but not knowing when; they do not know where they are in the process of dying. Progressing towards death from cancer is a decomposing process that, as most of the women in this study described and feared, is often untidy, unclean, and foul. Pearl, Christine and Brynne also alluded to that felt sense of looming when describing their fears that the cancer could suddenly accelerate and result in a rapid death. Christine recounts: “I’ve seen where persons are fine one day, doing well, and then six weeks later are dead.” Looming was portrayed as the constant awareness of mortality.

Assimilating awareness of mortality and grasping that death was less imminent required all the co-researchers to make another adjustment in their mental maps of how to live with death in the wings. None of the co-researchers have acquiesced to dying and all continue to aggressively treat cancer. Most of the co-researchers expressed that they no longer fear death as they did before. All five of the women acknowledged they have accepted that cancer kills and four of the co-researchers pointedly proclaimed that they were “not in denial” of the facts. Yet their level of acceptance and accommodation for death has been at different levels. All the women in this study except **Jo** believe that death from cancer is probable. **Pearl** describes herself as more realistic than most. **Christine** is reconciled with what is to come and tries not to dwell there. **Brynne** actively hopes for the best while preparing for the inevitable. For **Simone**, death is to be remonstrated against at any cost and holds out for a long life. How the co-researchers accommodated this shift in their relationship to the awareness of mortality was expressed in their attitudes, beliefs and values towards dying, death, and/or afterlife:



**Christine:**

I was told at Sloan Kettering don't plan on a long life. In my research – you kind of get overwhelmed going through everything then – okay, it is in your bones. It is not in your liver, lungs or brain. At that point everything was as long as it is your bones, it is not good but it is better. Then the minute it gets to liver, lungs brains you are hopeless. Subsequently, since then, I've actually met people who had it in liver, lungs, brains, yes, some have died and a lot recently, but others are still living and still managing. This isn't automatically the kiss of death. ...Yes, I've got metastatic cancer. I've got Stage IV. Yes, I am expecting that I will die of this disease but it isn't right there. It has more been just how am I going to get through this challenge and then that challenge and the next one. As opposed to you are now at the time where you look at your life and get your affairs in order. ...I never stopped and said, oh, gosh, okay this is it. I am going on disability. I can't function. I can't do this. My thing was always okay, how am I going to work around this. How am I going to incorporate cancer into my life as opposed to letting cancer run my life. That is still very important to me. I still think that is how I am dealing with it. That's how, for me, oh, my god, you are so good, how do you deal with it? I am like, I don't know. This is just me and this is the only way I know how. If I was another type of person I might be doing something else. All I know is me and my gut and how I have to do it, and this is what works.

**Pearl** expressed her lack of denial in comparison to others. “Denial is a nice place. I really didn't find a lot of comfort there. There are a lot of people who still don't get that we are dying. ...they are a lot more hopeful of a good outcome still. ...For whatever reason, I don't believe that.” She describes that she has integrated her awareness of mortality into a more universal perspective of life and death, hints of a belief in afterlife, and demonstrates her ongoing engagement with preparation for her death:

Life and death and life again is a natural part of how this planet works. You have lived, you have died, but it is not the end of the world. There will be life that goes on after. Things go on. They go on, and I go on. The other day I was listening to some music and a Beatles tune came on, “You say goodbye and I saw hello, hello, hello.” To me I thought what I great song to start my memorial service with, because you are saying goodbye to me, but I am somewhere saying hello, hello, hello, to whomsoever, whatsoever. I just thought it was kind of funny, but that is my way, a little wild. Everyone will be sitting there, quiet, quiet, quiet in the church or whatever

– not the church, but, you know – and then all of a sudden this Beatles song will come on. ...It is a great song. I don't know if I will actually get somebody to play that at my service. And, I will know. I do believe I will know. I believe I will absolutely know and be able to get a big chuckle out of it. What would be the point of making it funny if I don't get to laugh.

**Simone** was adamant that while she knows cancer kills and is afraid, she will not let that interfere with her primary and steadfast desire to stay alive:

The technology is only so good, and in the case of most people that have what I have, it is extremely likely that it [cancer] will come back because it is just too small a seed and then it will grow. ...It is just that possible things that are extremely improbable, I believe in them, and that I can do them and why not, until proven otherwise. That is not denial. Denial would be I don't have cancer. Or I have cancer but there is no way this could kill me. That would be denial. People with metastatic breast cancer are cured, just not very often. It just makes me feel – I don't know why it makes me feel good. ...Of course, I am afraid to die, but it is not really that. It is that I want to be alive. So both I am afraid and I just don't want to be dead at this time. ... I am not in denial. ... I believe in these possible improbabilities.

**Brynne**, clearly aware that her cancer is fatal, orients her life around hope:

I think we are all terminal. We are all going to die. I know that the science, Western science will support that there is no cure for metastatic breast cancer. They can get us into mostly short-term remissions, but there is no cure, so it is terminal. People live who have metastatic breast cancer. There are not a lot of them but there are some. There are people living who have had no evidence of any disease for 20 or more years, who had a very similar disease to mine. All it takes is knowing that one person has done that, then it could be me. It might not, but I choose to believe that it can be. There is no reason it should be this one and not this one. I'm terminal from something, and it may be from this cancer but it may not be.

**Pearl and Brynne** claimed that they no longer have a fear of death because of a shared spiritual belief in a transcendent universal energy. **Pearl** expressed that she is not daunted by death. Instead of believing in finality Pearl believes that the essence of a person's soul can never be destroyed and lives eternally. **Brynne's** current orientation to mortality was described in terms of a benign loving energy that after death visits the living:

I don't know what others would say about what happens when you die. I don't know how fully I embrace it. It is really strange. After I was diagnosed I had three really powerful visitations from my father that I can't explain. I don't really believe that he is in this format here floating around, but there is some message, some energy coming from the universe. I don't think those things happen inside my head. It just blindsided me. It was very powerful and very helpful. I guess other things have happened. I have had animal spirit guides appear to me at times of difficulty. You read about them, and this is exactly what should be happening, what I was looking for. So there is so much that we don't know. The more time I can spend being still, the more I can experience things that are out of our realm of consciousness and what we know. What I am sure of is there is this benign, really loving energy that exists. ... I think for a long time I believed that, in my heart of hearts, that we are alive, this is great, and then we are dead, and that's it. I guess I am experiencing different things now. I don't know that I would go so far as to say there is some grand purpose for everything, but there is an interconnectedness and there is this energy that is us and this consciousness that is us that isn't connected to our bodies.

After three years of becoming immersed in seeking knowledge about the process of dying and what shape death would take, **Jo** turned towards wondering about "what happens after this life" and investigated "mediums" who have contact with the deceased. She has adopted a more philosophical stance:

I think that like all the stages that we go through in life, and certainly it is pretty predictable that when people get to be somewhere in their 50's, that they will act a certain way. They will start realizing that, you know, life could be shorter, that they might actually die, that they won't live forever. I think that with the disease that you are going to act a certain way and certain things are going to be more important to you based on where you are along that path.

As she continues to live and the threat of imminent death recedes with every scan, Jo believes that it is very "possible" that she will "live another 10 or 15 or 20 years." She believes this even as she is undergoing current treatment for a recurrent skin carcinoma on her nose. "I had invasive squamous, within six months of having the invasive basal. The squamous was pretty scary. It is not as bad as melanoma, but it certainly is scary" because recurrent skin cancer can metastasize with a fatal outcome. In her shifting stance toward mortality, Jo directs her

attention away from death and turns instead toward the beliefs she's held for her "whole life:" "Show me somebody who did whatever it is that supposedly can't be done, and if they can do it, I can do it." And Jo would like a little more confirmation for this belief: "Of course, I always want to know how they thought they got there."

In summary, the five co-researchers experienced an intensified awareness of mortality. All the co-researchers described their awareness of mortality with the initial diagnosis of terminal cancer. The confrontation with impending death was met with an urgency to engage in one or more types of preparation. Some of the co-researchers ventured forward to face mortality yet not wanting to go blind from staring too intently at death, filed their awareness. When death exceeded their terminal expectations, when cancer was not synonymous with immediate death, most of the co-researchers were faced with reorienting their mental landscape and had to make accommodations for dying while still living. The co-researchers' described varied levels of acceptance and attitudes towards approaching death that was related to a range of factors: a Stage IV cancer diagnosis and prognosis; shifting emotional and cognitive lenses to match the changing conditions of living with advanced cancer and the constant threat of death; individual medical scenarios; and personal beliefs and values that were expressed in terms varying levels of hope, old or newly developed philosophical stances in regard to death, and whether death was viewed as the final event or as part of a continued life force that exists beyond consciousness.

#### *Living on a roller coaster*

Surviving longer than expected with a terminal cancer diagnosis was described by four of the co-researchers (**Pearl, Brynne, Simone, Christine**) as living in contradiction in an

unparalleled ambiguous time frame in which the women described how they are living and dying simultaneously. They talk of living actively with constant tangible reminders that they are dying. The experience was described using several metaphors: quicksand; walking a tightrope; dancing on a narrow edge without a railing; and as a roller coaster by three co-researchers. They portrayed that living was akin to the roller coaster white knuckled ride of extreme peaks and troughs, twists and sharp bends on a narrow metal track. But is not amusing and it's a ride from which they cannot disembark. For these four women, no matter what they do, the only exit from cancer and treatment is death.

They all recounted how their cancer “came back, even though they said it probably wouldn’t,” and “then it goes in remission and in a few months it comes back, goes into remission then comes back,” cancer growth slows and then in a short period of time the tumors progress, “it happens again” and again and again. It is the same with cancer treatment. The four co-researchers described that you go on chemo; it works for awhile, and then it doesn’t work and you go on another chemo. That works for awhile and then it doesn’t. **Simone**’s remarks that “there isn’t any end point,” where you can stop doing treatment and go on and resume life. **Christine** describes it as living stuck “like a hamster on the treadmill” for the rest of her life. Life in the co-researchers’ world is living in on a perpetual roller coaster with ongoing recurrence, feeling lucky but unlucky and fluctuating between good days and bad days sometimes on the same day.

All four co-researchers feel lucky to be alive, lucky to live longer than expected, lucky for current distance from imminent death, lucky that they can enjoy life, lucky to have not exhausted treatment options, and lucky that new drugs may be on the horizon. They feel lucky that they have had some amazing experiences, have nurturing friendships and more intimate

connections with family members all as a result of cancer. **Brynne** remarks that “I am lucky to have my partner...lucky I haven’t had to take some of the drugs others have...lucky that my strong-willed heart came out at the right time.” Paradoxically, the co-researchers also describe feeling “unlucky.” They mention feeling unlucky that they were diagnosed with cancer in the first place let alone having it become chronically terminal. They describe feeling unlucky that cancer is in their face all the time, unlucky with having so many medical appointments, unlucky because of the unremitting, debilitating and often residual effects of anti-cancer treatments, and unlucky for all the physical, emotional, and social losses they have suffered. They feel unlucky, tired, angry, guilty and depressed with being a “cancer patient” for so long. Simone debates the lucky and unlucky predicament and the emotional consequence:

I will get to feeling so sorry for myself, which is fine. I am totally entitled, I mean, about losses I’ve had because of this or that it had to happen in the first place, you know, at the wrong time when I had a healthy lifestyle. ... Then it came back. That is very unlucky, you know. Then I had to go through all that hell. That is very unlucky. ... If I look at the regular people, I am horribly unlucky or even the breast cancer rookies. If I look at the metastatic people, I am super-lucky. ... I am still surprised, just that things have gone so well. On the other hand, I had to go through a lot of hell and I wasn’t expecting that.

Good days and bad days are described by the Pearl, Brynne, and Christine as living with extreme physical discomfort and emotional distress on one hand contrasted on the other hand with an appreciation for the preciousness of time, profound insights, and newly realized joy, especially on days when feeling physically better. Good days are times to renew verve and for some, seen as transformational. Bad days are hard days on bad drugs with awful side effects, scary and worrisome because they could be perceived as the harbinger that the end is drawing closer. On the bad days, when Brynne, Christine, and Pearl are sick and feeling lousy, and cancer and the side effects of treatment intrude callously upon their lives, they have

wondered if this is “the beginning of the end.” And then, once again, the bad days pass and the good days return. **Brynne** described the contrast in terms of a month of good or bad days over the years of living longer with terminal cancer:

These really great days I am having right now might be really different in another month or two. I think once we are out of the really terrible time, we do our very best to forget it. If we had this interview two years ago I might be saying some different things...probably more tears.

**Pearl** describes this dilemma of the good days and bad days:

I have both kinds of days. I have both kinds of feelings. When you feel good, of course, you feel good. You don't forget that you are ill. You feel good and things go along normal, somewhat. When you don't feel good and you are laying on the couch or whatever, you begin to think, oh, is this the beginning of the end. Is this going to be progressively debilitating? Is this how I will feel every day and not feel better again. For me the conundrum has been that I have both kinds of days. Emotionally I have both kinds of feelings. Like I feel terrific and I do a bunch of stuff and then all of a sudden I don't feel terrific and I think, woe is me, this is the beginning, and then I bounce back. I go, oh, well, that was just an episode. For me it is trying to remember on the days that I don't feel good that it isn't the beginning of a progressive demise, but it is just episodic. I really try to remind myself of that, but it is hard.

All four co-researchers portrayed living as an unending struggle to stay alive and cope with the “unknown.” On bad days the co-researchers spoke of living with constant uncertainty of when cancer will not only result in death but destroy their quality of life beforehand.

**Christine** characterized this as:

I would almost rather have two years and say, alright this is it. I am going to have two years. I am going to have a good quality of life. Let me do what I want to do. Then I do it, focus in on that...I can then manage my time, as opposed to ten years, getting progressively worse, am I going to be able to do this, how it is going to work, how it is going to happen. That is the part that is harder. It is harder for me having the unknown of what's out there, and not knowing what your quality of life is going to be.

It is in the midst of this struggle between the good days and bad days the co-researchers mull over the question of when is enough, enough. It is a question about the quality of their lives. **Pearl** ponders the question:

How much of this will I tolerate? ...Will I continue treatment? ...Just how much more treatment would I agree to? ... Is there an end point where I won't tolerate feeling bad? That's a really tricky one, because when you feel bad, of course, on a scale of 1 to 10, you think you are a 10. The next day you feel better and you think, oh, that was really only a 3. I could feel so much worse. But you don't know that when you feel bad.

**Brynn** remains resolute that there are "ways I won't live. ...the issue is really clear for me and it is clear to my doctors that my concern is my quality of life." **Christine** asks herself "how long do you do this?" She clearly understands that in the future, the struggle to stay alive could become an option she may no longer choose when she has had enough. The three co-researchers voiced that they know a time will come when they will want to make the decision to stop treatment but presently they are troubled by not knowing yet, how to recognize *that* time.

**Simone** indirectly spoke of the good days and bad days describing the physical impact, the emotional perils, and how extremely difficult it was to live with uncertainty. However, she emphatically stated that no matter how bad her quality of life became, she would not be wrestling with the decision of when to stop treatment. Simone related that this was not an option open for any consideration even if she lost the use of all four limbs. She declared that staying alive was worth paying any price.

**Jo** was not included with the co-researchers who described living on a roller coaster for she has been in long-term remission. She did not describe her days as split between good and bad. Jo referred to luck, however, she did not ascribe a cancer diagnosis to being unlucky



nor did she attribute her remission to luck. Jo attributes longevity to her hard earned efforts with complimentary and alternative practices and lifestyle changes. Yet, even Jo, who has been in long-term remission and is not currently experiencing any physical indicators of the disease's presence, grapples with how to prevent a recurrence with a terminal diagnosis. Jo questions what components of the treatments she actively utilizes are effective and hunts for validation and how to live with an acceptable quality of life:

Sometimes I ask myself what about the aromatase inhibitor. If I knew for sure that I would be able to sleep if I stopped it, I would probably take my chances, getting scans on a regular basis, for that quality of life and being able to get off the sleeping pills. ...I would take my chances on recurrence showing up and get off it. Maybe I wouldn't take hormone replacement. ... It is just like all the other stuff. Some days it is like, oh, I don't want to make my drink again today. Is this green stuff I am putting in, is it really helping me? Is the flax, is it this, is it that. I just spent hundreds of dollars on supplements yesterday. Does this really work? Well, I don't know anybody else who is doing it. I don't know anybody that can say, well, I do all that and I am dying anyway.

In summary, living on a roller coaster is having to cope with the extreme highs and lows of ongoing cancer and treatment. It is feeling lucky on good days and unlucky on bad days and trying to recognize and decide when enough discomfort and diminished quality of life will be more than enough.

#### *Feeling different from others*

All five co-researchers by exceeding their expiration date and still living with Stage IV cancer perceived themselves as different from others. All five women cherished or expressed a desire for connectedness which in turn underscored a feeling of being dissimilar and alone in their plight. **Jo, Pearl and Christine** alluded to this sense of separateness in expressing feelings of guilt. Pearl feels guilty about all this dying stuff taking up other people's time. Jo

feels guilty that she has been in longer term “remission especially when people say things like, you are so lucky.” Christine feels guilty for not always being as appreciative of being alive with advanced cancer as do others.

The five women described that their experience had created a chasm between them and others who never had cancer, others who had completed treatment for early stage cancer, and even from other persons with cancer metastases. All five co-researchers viewed their difference from others in terms of being misunderstood. **Simone** described her anger over being misunderstood when she was having a rough time in the hospital:

It was really frustrating because nobody understood and they would come up with these dumb-ass suggestions like, have you tried applesauce? I am like, no dumb-ass, I didn't think of that. I am starving here. I am literally going from 115 to 85 pounds, but no, I didn't think of applesauce.

**Pearl, Brynne, Christine, and Simone** mentioned that their outward appearance was a contributing factor in being misconstrued as their cancer is outwardly invisible and reveals nothing of the disease process on the inside of their bodies. On “the outside” they all look “fine” and “fit” in the eyes of other. In the public domain, Pearl and Simone mentioned how cause-marketing practices (marketing practices that capitalize on the promotion of a cause) perpetuate misunderstanding of their condition. **Simone** was indignant when referring to the proliferation of pink:

Look, this is serious. This is not pink glitter. It seems like in the culture now, just because of the media and commercials and we are going to have the pink peppermint patties and the pink M & Ms and the pink rubber gloves – I've seen all sort of stuff, pink mixer. The idea – I get the feeling that most people think that virtually everyone survives breast cancer. People go around wearing pink t-shirts and pink earrings...It bugs me that with any cancer it is just when you have too much like glittery things and rah, rah, isn't this great, we are survivors, people forget what it is about. It is just a social event now for some people.

With the non-survivors, **Pearl's** feelings of being different derive from her experience in which others have felt the need to treat her differently. Pearl differentiates herself in explaining that “there is this weird thing that happens when you talk to lay people. They are less likely to get it. ...and they all have way more problems than I have.” Pearl intimates separateness from her immediate family members, even as she draws closer to them. Pearl alone takes charge of “protecting” family members from the burden of her illness and death by deciding the flow of information and making the preparations for them.

He doesn't come to all my doctor appointments like other husbands do, and he would if I asked him, and he would if I said I wanted him there. But I feel like toward the very end, there will be enough in-your-face shit from my family and they will be there. So during this interim it doesn't have to be rubbed in their nose every day. It doesn't have to be rubbed in their nose once a month. They get it, and it is probably a roar in the back of their heads at all times, but I don't need to be constantly rubbing their faces in it. So I do try to filter for them. Because I am the health care executive in the family, they look for me for interpretation anyway. What does this mean?

**Brynne** described how she treasured connection with friends, with her partner and the open communication between them, and most importantly, with her spirituality. While Brynne has grown more intimate with her partner and found “peace” in her “connection with the universe,” these connections have heightened an awareness of her difference from others diagnosed with cancer:

It [diagnosis] really did get my attention in a way that doesn't happen for everybody I know. Some people don't change their lives really at all. I watch the different ways that people handle this kind of a diagnosis and this kind of a life. ...I know there are many people who just ache for the life before cancer... but I am much more settled and peaceful and complete.

**Simone** and **Jo** portrayed how they feel “alienated” from everyone else with cancer with the comment that “you are not like anybody else and you don't have anybody to talk to”

Jo spoke of “this wall between me and others.” Simone talked extensively about feeling misunderstood and lonely. Simone disclosed this felt separation from early stage cancer survivors:

I feel very jealous of people that just had one thing, stage one or something and took care of it and they are fine, and especially if they are really out of shape and don't do anything to try to take care of themselves. ... They feel very proud of the fact that the bad thing didn't happen to them, which they should, I guess. It is just painful when they say it. ... like a superior attitude toward me, and it is really just basically they don't want to make whatever mistake I made. If you go into a regular breast cancer group and a lot of times people just start peppering you with questions like was it in your family. Where are you getting your mammograms? Did you smoke? It is like they are trying to put you in a box. I understand it. We all want to control it, but it makes me feel so alienated.

Simone and Jo portrayed their yearning for persons with whom they could connect and mutually share their life situation. Simone wants to be understood: “I know the world doesn't revolve around me, but if there were just a few more people that understood, that would be all I would need.” Jo emphasizes her difference and longing for connection in desiring company, commonality, and validation:

Whenever I meet people that do have the same disease as me, they are usually behind me in terms of being diagnosed with it in the liver. I've actually been thinking about maybe going to some of the cancer websites trying to find other women that, you know, have been, had it in some organ, not bones, because you can have it in bones forever, but somebody that has had it in an organ and that has been in remission as long as me. ... I mean that if I could meet up with someone who has had a similar diagnosis and not even breast cancer, but any sort of serious cancer. . . I know everybody thinks they are going to die when they get diagnosed, but we are talking people who really don't have a big chance of outliving a 12 or 18 month – to know somebody who believes and practices all the stuff that I do. The nutritional piece, the exercise piece, – to me even if someone who does partly what I do, I guess would give some validation. People made me doubt that having a positive attitude, you've heard it, “I know a lot of people who are dead that had a positive attitude,” so I guess I just don't feel like anybody gives any validation to what I do. ... I guess it makes me feel like I am not alone when you can validate how you are feeling, that someone else is in the same place and feels the same way. ... share whatever it is you are going through, that somebody else is doing it too.

**Christine** values the connection she has made with other women with Stage IV metastases and feels less alone. At the same time, because her cancer spread is still confined to her bones, she expressed feeling different from these women:

I have been living with it for seven years, but I also haven't been living with it the way some of these other women have... who are so constantly in it. I've had that luxury of having it there, but being able to step back. In some ways part of me feels like phony. ... I kind of feel like, oh, my god, these people are much more serious than I am, but mine is as real as theirs and I know that in my head. But it is not to say that sometimes my gut doesn't.

**Pearl** verbalizes feeling different from others living with Stage IV cancer based on her perceived proficiencies: "I get that part more than others. ...Because of the resources and skills I have, should I be going through this differently than others? ... Their prior experiences don't let them integrate it the same way mine do." **Jo and Brynne** express feeling different from other women with terminal cancer who won't try the complimentary treatments that they found effective for themselves. **Brynne** disclosed frustration with the dissimilarity:

She was having nausea and she was losing tons of weight and she wouldn't take any of the anti-nausea stuff... I guess those are things that are sort of beyond me. I gave some anti-constipation Chinese Herbs to one woman who was clearly suffering. She came back and said, oh, I can't drink that. It is too terrible. To me it is like nothing. I try to get people to go to acupuncture...they don't go...I get frustrated.... it is really painful.

**Jo** described bewilderment in feeling removed from others: "Why are people so resistant to making changes that would extend their life. What do you have to lose if it doesn't work? ...I get irritated with people. ...I guess we can't all be crazy committed like me."

In summary, feeling different from others is feeling different from most every one the co-researchers know. It is feeling different from those who never had cancer and different from those who want them to be well and perpetuate media myths of a cure. Feeling different

from others is treasuring the connection with family and friends and feeling separate from loved ones who must be protected. The co-researchers feel different from early stage cancer patients who put them in a box until they figure out what to do so as not to be you, the one with cancer metastases. They feel different from others with metastases that all appear worse off than they and who don't utilize practices they believe to be of benefit. Feeling different from others includes feeling: guilt, unacknowledged, misunderstood, alienated, invalidated, exceptional, and alone striving for connection.

*Interaction with medical systems and treatment protocols*

All five co-researchers in this study conveyed their experience in the medical world. The five women talked about the impact of treatment, treatment preferences, their interactions with both the Western medical and CAM systems, which included their relationship with and expectations of medical professionals. The five women all described extreme discomfort and incapacitating effects resulting more from cancer treatment than from the cancer itself. "Profound fatigue" was mentioned by most of the co-researchers as the most disconcerting side effect from anti-cancer drugs, radiation, and surgeries. **Brynne** relates the fatigue directly to treatment: "There are some treatments that cause a lot of fatigue...drugs that make me really tired. There are days when I get tired. I think most of it is taking chemo." **Simone** sees the chemotherapy effects of fatigue in every day endeavors: "I get tired if I do too much, like go to K-Mart and walk around too much. I am exhausted." **Pearl's** describes how fatigue interferes with engaging in enjoyable activities and the simplest of tasks:

My first notice of being fatigued like that was not having energy to do things you like, so not being able to read. You are laying on the couch. Why can't you read? You just can't. It takes too much energy to focus, to turn the pages, to remember the storyline.

...There are the things I intended to do. Now I don't have the energy, stamina, fortitude or interest.

Pearl aptly illustrates the experience most of the co-researchers expressed in her description of being too tired to even to have a personality:

It's that profound fatigue. Even when people call, I have found that there have been plenty of times when I don't have the energy to smile while I am on the phone, to put that lilt in your voice, to say hello. The way I defined it is I don't have enough energy for personality. I never had any idea how much energy personality takes. People have said to me all my life, oh, you have so much energy. I never quite got that. I mean, unless you are running around like some sort of a whirling dervish, I don't know why people would say that. Oh, you have so much energy. Sometimes they say it when they are just visiting with me and I am not running a marathon. Now I kind of get it because it takes energy to be personable. People call and you are like, [whispers] oh, god, why do I have to talk to her. They want you to have energy on the phone and I don't wanna. I actually screen calls— that is actually the only time in my life I've ever screened calls. I don't want to talk to people, even though they're well intentioned.

Impeding their ability to carry on routine functioning, all of the women mentioned one or more other physical side effects: insomnia, nausea, mental fogginess, bowel irregularities, sexual dysfunction, neuropathy, and the blisters that accompany hand and foot syndrome. **Brynne** conveyed the wretchedness of treatment: "I was blistered from my eyelids to my butt, inside and out. My mouth would be blistered. I couldn't taste anything. I had terrible, terrible intestinal cramping." **Simone** told of similar misery: "I literally threw up everything I ate. What I could eat, things would just burn like crazy. It wasn't that I couldn't chew or swallow, it is that if I did, it would be like I swallowed acid, like lye or something. ... It was just the most horrible time of my life and I felt really scared."

**Jo and Brynne** spoke of the sexual side effects of dryness and thinned tissues interfering with intimacy. **Jo** talked about a myriad of physical and emotional symptoms she experiences because of her medical treatments: "Diarrhea is just sort of a way of life for me.

...I am getting four hours of really sound sleep and then I wake up, and start to toss and turn and not be able to stay asleep. ...have had fungal infections, unbelievable itching, anxiety, skin rashes, weepiness, irritability, night sweats..."

The emotional impact of treatment was described as equally intense. **Christine** disclosed emotional fatigue as a result of medical procedures: "I am tired and sick of it. ...I just get sick of going on." As did **Brynne** "The biggest intrusion is just being so tired of it all." **Pearl** tries to avoid getting caught up in her emotions: "You just try not to think about that, of course, because that is a really big pity-pot vicious cycle. You can really get caught up in that emotionality. I try not to get too caught up in that, because that really doesn't serve any purpose." **Simone** divulged the dark side:

It is just hard, because you get emotional. ... I just live in this – it is like a black cloud hanging over my head and I try as hard as I can to ignore it and figure out ways to manage it, because what is the point of trying so hard to be alive if I am just going to feel bad. ... It is so hard to just live and try to be happy and it is not like I am never successful at it, but it is just always, always there ... I get really angry.

Treating their cancer is "all consuming" for each of the co-researchers. Most of the co-researchers described that the average week is not normal unless it is filled with multiple appointments for some type of medical intervention or complimentary therapy. Living with terminal cancer dictates a daily focus even when in remission. **Christine** summarizes the medical aspects that were voiced by all: "I am either at the doctor's, I have physical therapy, I am going to a support group, I am going to therapy, I am going to get scans."

To assuage the impact of side effects and to buffer their chances for containing the cancer, all of the co-researchers utilized more than one type of CAM remedy. **Jo, Brynne, Pearl, and Christine** are all engaged in a combination of complimentary practices. The types of CAM that were mentioned included: yoga, meditation, Chinese herbs, vitamins and



supplements, nutritional counseling, dietary changes, inclusion of organic foods, psychotherapy, vibrational healing, acupuncture, and expressive arts. **Jo** stated that “she has done it all” and described the weight of doing a rigorous complimentary regimen:

There was a while there where my husband would come home and be like, did you do your green thing today? Stop. Oh, you didn’t? I am like, you know, I can miss a day. Well, did you do your guided imagery, did you play your bowl, did you walk, did you exercise? What did you do? Did you do your yoga? Like, back off. It is too much responsibility sometimes.

All five co-researchers do not believe that the Western medicine can offer them a cure for their cancer but they do believe that Western medicine, although insufficient, has prolonged their life. Only **Jo** believes that she may have cured her cancer but does not for a moment think of stopping treatment. Out of the five, four women believe you cannot cure cancer but can live for many years with a diagnosis of Stage IV cancer. All of the co-researchers have placed their faith in new drugs, complimentary and alternative medicine (CAM) which includes utilizing psychological support through engagement in therapy. They believe like **Jo** that if there is at least one other who has beaten the odds, survived for a very long period of time, than they can too. “If they can do it, I can do it.” The co-researchers, having located few others, recognize that they represent a small, but growing sample of people with advanced cancer who have lived beyond the expiration date. **Simone** believes you may be able to beat cancer for many years. **Brynne** acknowledges that as of yet there is no cure for cancer. Brynne believes that she can exert some control over her cancer by talking with it. She also believes that with CAM and working on yourself you can heal and make peace with your cancer which in turn could add years to your life. **Christine** believes with new anti-cancer developments emerging all the time that life can be prolonged, especially if treatment keeps the

cancer from traveling to an organ. While **Pearl** continues to aggressively treat cancer, she pragmatically believes in the inevitability of the statistics and probability.

The five women view their oncologist-patient relationships as both special and disappointing. All the co-researchers talked of having established a good working relationship with their doctors. While the women expressed confidence in their oncologists and valued their professional care, they asserted that their view of doctors as experts had dramatically changed. **Jo** talked about no longer “buying into” everything they say. For all the women, disappointment descends in regard to not receiving answers about how much time they have left to live and what treatments will be effective to stave off progression. **Christine** remarked that the doctors cannot tell her anything about how fast or slow the cancer will spread because they don’t know. All five co-researchers’ expression of their frustration with not getting such answers is encapsulated in **Brynne’s** statement: “They shouldn’t tell you anything because they don’t know. ...I came to realize fairly early on that they had no idea how long I would live.” Their dissatisfaction extends to the Western medical model as a whole; the women all mentioned that medical technology and knowledge of how to treat advanced cancer is critically lacking and not fully trustworthy. **Pearl** described her doctor’s recommendation for treatment based on treatment protocols as a “crap shoot.” **Simone** voiced regret in recalling her first cancer diagnosis: “I was thirty years old. ...It’s one of the biggest regrets in my life and I hope I don’t regret anything more, but I was just so innocent then. The doctor said he thought I didn’t need any other treatment. I think most doctors would have said that, but I just wish I had gone for a second opinion, because I did need more treatment.” **Pearl** further related feeling a sense of betrayal and annoyance in dialoguing with her oncologist:

I did have a conversation with my oncologist the last time I went for the purposes of asking these kind of metabolic questions. What is the doubling rate? Is there an acceleration as tumor load reaches a certain point? Of course he had no answers for any of those very thought-provoking questions. He did say they were the most thought-provoking questions that he had been asked, but he didn't have any answers. So that really didn't help me.

**Simone** pointedly recalled interactions with doctors where she felt deprived of dignity. Non-oncology doctors are viewed by Simone as clueless: "I could go into some doctor for a stubbed toe and they would say it was a metastasis. You can't go to a regular doctor if you are somebody like us. They think everything is caused by that[cancer]."

In summary, the interaction with medical systems and treatment protocols involves all consuming medical care with conventional treatments that cause unrelenting severe, intensely discomfoting and disabling side effects, to keep the co-researchers alive. The interaction with medical systems engendered disillusionment, disappointment, and diminished trust in Western medicine and in doctors as the "experts." The harshest of disappointments to bear is living with uncertainty and the fatigue that surrounds it all. At times, when their dignity is challenged and they are pulled under a cloud of blackness the co-researchers try not to drown in feeling sorry for themselves. Knowing that Western medicine cannot provide a cure or ease their distress, the co-researchers seek CAM hoping for a longer life and for relief of physical, psychosocial and spiritual discomfort.

*Cancer invades and changes how you live and re-view life*

Cancer in the lives of the co-researchers is viewed as an outsider, an intruder with a force of its own that has to be tolerated. For most of the researchers cancer is something that resists control. The women referred to the invader as an "it," "something that doesn't belong

in there, that is growing and pushing.” Advanced cancer invaded the bodies of the women in this study and drastically altered the way they live. Cancer shoved its way into their work, their identity, their social lives, and compelled them to examine their faith and seek meaning. The co-researchers spoke of cancer’s force in defining, restraining, and/or providing them with an opportunity for growth.

Living under the rule of the invader was described as “hard.” “Hard” was the most frequently used word by the five co-researchers in describing how their lives have changed. In contrast to the relative “ease of life” before cancer, the descriptions included that it was physically, emotionally and socially hard: hard to face cancer every day; hard to endure the side effects from medications; hard to advocate for oneself and be disappointed with medical professionals who do not have definitive answers; hard that medical technology is lagging; hard to remember that you are not yet dying; hard to keep up the struggle to stay alive; hard to have cancer change your preferred way to live; hard to live with the unknown; hard to figure out how to spend time; hard being misunderstood; hard to comprehend others; hard to listen to people say stupid things; hard feeling alienated; and hard to talk to family members about being tired of it all. The co-researchers described that surviving longer with terminal cancer makes it hard to live and hard to die, and how all of that is hard on friends and family.

Stage IV cancer was not seen by any of the co-researchers as a gift. **Pearl and Simone** both expressed the following: “Cancer is not a gift. If it was I would want to put a bow on it and give to someone else. This is not a gift to give to somebody I care about.” Simone explained further that “there are others who say that ‘breast cancer is the best thing that ever happened to me. It taught me to appreciate my life.’ I’m not saying everyone is there, but I guaran-damn-tee you, most of the people that say that it [cancer] is a gift thing are not

metastatic.” **Pearl** stated that she was already satisfied with her life and does not see cancer as adding any new opportunity to improve upon her life. **Christine** echoed similar thoughts: “When I hear the oh, gee, ‘I’m so glad I got cancer, this diagnosis. It has been that epiphany.’ I want to say up yours. [Laughter] I’m sorry it wasn’t an epiphany for me.” However, **Jo**, **Christine**, **Brynne** and even **Pearl** talked directly about one or more “riches” they have garnered as a result of having terminal cancer. **Brynne**, unlike Christine, voiced that cancer has been transformational: “I wouldn’t give it to anyone, but there are gifts in it. There are qualities of my life that are much richer. ...I feel more joy on a daily basis than I felt pre-cancer.” **Pearl** expressed feeling more enriched by all the friends she has made as a result of having terminal cancer. **Jo and Christine**, dissimilar to Pearl, revealed that terminal cancer has given them the opportunity to reevaluate their priorities. Christine remarked:

It does make you look at things a little differently. In terms of that, and I’m not glad I have it, but it has given me an opportunity to look at my priorities. Why am I doing this? ...We are just going down the path, doing whatever, but what am I doing it for. It is okay to work. It is okay to make money to do this, retire, whatever. It is like wait a second. Why not do some things now.

Cancer’s invasion has generated fear in these women’s lives. Most of the co-researchers were less afraid of death itself, and more in fear of how cancer takes over their life, what they have had and will have to do to live. They expressed fear about dying in terms of when treatments stop being effective or when there are no longer any more treatment options. But mostly, the co-researchers described fear of pain, suffering, and losing control that accompanies ongoing deterioration and progressive limitations imposed on their physical functioning. **Christine** fears addiction to her pain medication. **Jo** fears becoming addicted to her medications for insomnia and anxiety. **Pearl and Christine** fear becoming a burden. **Pearl** fears being unprepared and leaving unfinished business. **Brynne** fears the misery of anti-

cancer medications. **Simone and Jo** fear loneliness. Pearl, Brynne, Christine, Simone and Jo all expressed directly or indirectly fear of wasting time.

For some of the co-researchers, fear of wasting time has restrained how they live. **Simone's** fear of wasting time restrained her medical decisions: "I had a radiation oncologist I couldn't stand. I just stayed with her because we had wasted so much time." **Pearl** fears wasting time in struggling with preparing for death too much or not enough. Fear of wasting time has also been a motivator for most of the co-researchers. **Simone** expressed not wanting to be years down the road, looking back and "going, wow, I wasted my whole life being afraid." **Pearl** has "tried to finish all the unfinished projects or the planned projects that are in my closets, so that I get them sewed up before I die." **Brynne** described her delight in taking time to think things through and enjoy life more with traveling. **Jo** explained that time now allows her to get pleasure in the ways she imagined with retirement. **Christine** summarized the sentiment of all of the co-researchers:

There is a definite difference, I am not putting things off, I am not waiting, which I think I totally would have done in the past. ...Now it's what do I want to do and how do I want to live my life. ...giving myself time to do those things, things that I might enjoy, which might be very simple, but a little more creative and fun than in the past when I am busy and just going. It's saying this is what I'd like to do so give myself the time to do those things.

All five co-researchers described losses in the context of defining themselves by who they were in the past and what they had been doing. **Brynne** talked about losing her hair and its relationship to her self-concept:

If you take the hair away and the eyelashes and if the eyebrows, too, that's an issue. It just messes with your self concept, your self esteem. I found I had to work harder to continue feeling good about myself. It is not impossible to do, but I know, for me it was really part of my identity. It was really part of how I define myself.

**Brynne, Jo, and Pearl** described how their self identities were defined largely by their careers. Yet to survive longer with advanced cancer, all three co-researchers had to give up their jobs. **Jo** described going through a crisis of “who am I now” after deciding to leave her highly successful and lucrative career. **Pearl** described that her identity was wrapped up in all the ways that she “used to be,” “used to have,” and “used to do” both professionally and recreationally. Now, she struggles to redefine herself and how to live.

I am used to doing things that are published, that are important, that make a difference, that get both recognition and reimbursement. So it is really hard for me [not to work] .... I am also used to my work nationwide having it published, having it recognized, having people court me to do the work. We would love to have you as a consultant on this project if you are available. That is all ego work, but I am used to that.

**Brynne** spoke of the loss of work but also of the rewards of not working: “On the one hand it was devastating because it was my baby that I had worked. Not working was hard to get to. ...But there is the gift of waking up each day knowing that this is your day and you decide what is in it.” **Christine** described not yet relinquishing her career, but has had to take a step back and reprioritize now that cancer is progressing more: “It’s now where I say I want to work part-time. I don’t want to work full time.” **Simone** has worked as she could throughout her diagnosis but is beginning to question her job now that she wants to shake off being defined only by cancer:

I have just been cancer woman for so long that I don’t want to be cancer woman. I don’t want that to be my identity. I’m still working on my identity, like things I can do instead of have cancer, a hobby or something. ...And the thing is work is a little bit of problem because sometimes I don’t like it and some times I do. I can’t really decide what to do.

For all five co-researchers paid work shifted to the high price they pay to stay alive and the unpaid toils of working on themselves. All of the women brought up working on

themselves psychologically. They all expressed similar sentiments to what Simone succinctly stated when she described wanting to becoming more adept at expressing and dealing with her emotions: “I still have all this emotional stuff that I don’t know what to do with, but I am working on it.” **Brynne** explained: “I’ve been in and out of therapy because I wanted to work on these issues...work on the anger...not stuffing it as much. ...I do really intense work when the cancer is growing.”

Another aspect of psychological change all of the co-researchers portrayed was recognition of what was uncontrollable and a greater sense of agency over what they could control in their lives. The women all referenced how they are choosing to take more control over their medical regimens, choosing how they want to live, and for most of the co-researchers, as discussed previously, choosing when they may want to stop treatment and how they want their death to be commemorated. In addition to choosing how to manage her feelings, **Simone** described taking more initiative in reference to treatment: “I’ve always gone with what my doctor thought was the best thing, except that I talk him into being more extreme;” she requested and received additional and more aggressive chemo than what was standard protocol. **Brynne** described her sense of empowerment in relationship to her doctors and medical decisions:

I feel like I am making decisions for my life and my body. And that’s really empowering, rather than just letting go of control and seeing what they are going to throw at me next. The decisions aren’t always pretty, but it is empowering to know that you get to be the person making that choice for your body, that if it is going to be something that is really hard, that you get to make that decision. It doesn’t just happen to you.

**Brynne** also described a sense of agency in deciding to stop work and the transformation that ensued:



There was a sense of urgency initially. What am I going to do? I knew I didn't know. I spent my life as an adrenaline junkie which is the worse thing you can do, for me, to feed cancer cells. Just giving them all the food they would ever need in case they wanted to grow, they had it. Realizing that I had some control in this matter. ...What do I need to do immediately? Not to work, and to take this stress away. I need to start breathing, be quiet, be still, listen to my body. I don't feel urgent about it anymore. ...I am not jumpy anymore. I don't need lots to be happening to be happy. I am more present with people. Just enjoying them, but also thinking about three other things: I am really more often here. ... I like how I feel ... there are qualities to my life since the diagnosis that are so much richer.

**Christine** described that undergoing treatment procedures were all her choice as was sadly choosing to not to have children because of cancer and treatment. **Pearl** described learning to choose on a daily basis between the fine lines of altruism and setting boundaries for self care. **Jo** talked about choosing to stay committed to her CAM regimen.

Cancer growth has also propelled the co-researchers to reflect on spirituality and to probe for meaning and purpose. **Pearl, Brynne, and Jo** sought and developed deeper connection through spirituality as a result of their living longer with advanced cancer. For all three co-researchers spirituality was not defined as organized religion. **Jo and Brynne** gave up the Catholic faith of their families in exchange for delving into the realm of "spirituality." **Pearl and Brynne** talked of spirituality in terms of connection to the universe. **Brynne** described how "taking time to connect with my spirituality and spiritual beliefs, which I never did before" was greater than anything she had experienced in any previous year of her life. **Brynne** described the sheer joy and love that comes from her spiritual connection which in turn gives her life meaning. A meaningful life is also one in which she can give something back to others. **Pearl** claimed never to have settled on one religious faith and has found through her yoga practice the spiritual connection she was seeking:

I have wanted a yoga practice forever... I kept trying to do yoga, but it was more – maybe I wasn't ready for it. I was still in the aerobic mentality of no pain, no gain. I was doing it more for physiology rather than spirituality. Because I don't have a religious practice, there was always something missing that I wanted to have this sense of, I don't know, comfort, structure around a practice, but I never had the time or never spent the time to go find it. I hardly ever went to temple, occasionally went to churches, and I kind of called myself a Unitarian for a while, but I had never been in the Unitarian church whatsoever. I just assumed I would get along with those people better because they are a little bit more open minded. But this has actually become my religion or my practice, and this particular teacher, she is amazingly connected to whatever is going on this planet. Yoga is helping me open. I think I was always kind of connected but I wasn't open to the flow. I wasn't letting it flow. ... For me, it isn't about can you touch your toes or whatever. It is really about – first of all, the Dharma discussion.

**Christine** described that she has a more scientific approach to life than faith-based.

In identifying with Judaism she conveyed values often associated with what gives her life meaning:

I've gone through my own process about a spiritual God and various things like that. I am more of the belief not that God created man but that man created God. ...I am more scientific and the big bang and all that. I really like the fact of Judaism that we don't believe in an afterlife. It is more what you do on this earth and being a good person. That is what is important. It is not all for the next life. On the other hand, I have known people, like D. I admired her spirituality. I was a bit envious of it, of somebody who has that belief and can put that utter faith into that, that gives them a sense of security. I think that can be a wondrous, wondrous thing for that person. I can't go there. I don't buy it. ...There has been a lot of years in processing. I think I have found something that is good and works for me. I am really lucky that I think in Judaism there is the two. You can be a very proud, strong Jewish person in our heritage without having anything to do with the religious side of it. It is a nice balance.

**Simone**, like Christine, envies others who have a strong faith: "I wish I did have a faith. These people find it so comforting and I would love that. I really do. I wish I could just instantly make myself have some kind of nice, tolerance toward other religious faith. But you either believe or you don't believe." Simone referenced meaning in not wanting to live any longer with fear, bitterness and loneliness while declaring that her sole purpose was to put her

energies into staying alive. **Jo** described her connection to spirituality as being curious about what happens “after your heart stops beating.” Jo described several attempts she has made to find her purpose in life. When she described her recent search for meaning and trying to figure out what she is supposed to be doing, Jo alluded to believing in God. Jo described how her search for purpose was based on what she read in a popular book:

If we can just find that blackboard in the sky that our purpose, you know, the purpose God has for you, [pause] we are going to find the answer somewhere out there on this blackboard. Well, the reality of it is there is no blackboard. The reality of it is, God did not give you a purpose. He did not give you like a chore. It is up to you to decide what your purpose is, and you can write in what that is on that blackboard.

In summary, the invasion of cancer changes the co-researchers’ bodies and their lives. Inwardly and outwardly, cancer changes how they live. Cancer is a force that brought new fears, left a trail of losses, and for a few engenders new insights and appreciation. Cancer forced the women to change how they work, forced them to revision their identities, change how they related to the time left, their quality of life, and to spirituality. Contending with the force requires fortitude and for some of the co-researchers resiliency ensues. None of the co-researchers are grateful for the harshness cancer has thrust on them, but in the hard work of coping with cancer and in reexamining their priorities, they have discovered the freedom and responsibility of choice. For some of the co-researchers choosing leads them to spirituality that creates an opening in which connection and meaning can flow.

### *Individual Structural Description*

The individual structural description moves from the textual facts toward the meanings and essences of the lived experience through the process of imaginative variation. Imaginative variation as explained earlier “approaches the phenomenon from divergent perspectives” (Moustakas, 1994, p.97-98) to ask what structural elements were present for this experience to emerge. This process moves from the appearances of “what” the experience was for each co-researcher towards understanding “how” the feelings and thoughts of the experience of the phenomenon were aroused. From this process, the fundamental elements, the invariant structures are identified and a vivid description of the underlying dynamics and structural elements of the themes and qualities is composed for each co-researcher. To illustrate this aspect of the data analyses only one co-researcher’s individual structural description follows.

#### *Pearl’s Individual Structural Description*

The structural elements of how Pearl experiences living past her expiration date and still living with Stage IV cancer relates to universal structures and to her unique set of values, beliefs, strategies and ways of making meaning. How Pearl experiences this phenomenon includes her self in relation to lived time, space, and body, in relationship to her self-identity and in relationship to others.

Pearl is in a conundrum in relation to time. Living longer with terminal cancer has turned her world upside down and dumped Pearl into a conundrum of not knowing how much time she has left to live, how to live best within that time, when time is near the end if she will be able to recognize that this is the end, and if she will have had enough time to

prepare for the end. Pearl has lived longer than she expected and yet she anticipates living much shorter than most. Time for Pearl has been disrupted. Experiencing discontinuity with her past and feeling unable to make long-term plans for a future life sends Pearl plummeting into a void. Lost in time and space, she finds herself in a state of “inertia” and grapples with how to move in time while holding simultaneously, seemingly opposing realities of dying and living. Looking backwards at how everything “used to” be Pearl focuses on “preparing” for future death and struggles with how to live in present time. Time lived is now a race for which she has not trained and in which there is no algorithmic way of knowing how far she has left to go. Time is lived incongruently in shuttling back and forth between days of feeling bodily well or physically horrific. Her body, once private space becomes public domain, a receptacle for innumerable medical intrusions in public settings. Her time in this lived space becomes defined by the boundaries of science, the limitations of what medical treatments are able and unable to do. Time is an unending calendar of innumerable medical appointments. Yet, time cannot be pigeonholed into exact months, days, or hours to ease Pearl’s angst from not knowing death’s proximity. As Pearl lives longer, as time temporarily stretches between life and death, she has recently found a spiritual practice that offers her moments of being in the “flow” of time. In that flow she can accept bits of randomness. With that acceptance Pearl finds herself, after considerable planning time, engaging delightedly in some activities she previously rejected. This movement, an opening to all of life, reinstates a sense of comfort and structure. Having structure has always been a soothing time for Pearl. For most of Pearl’s life “taking charge” of “what to do” with time was more important than “being” in time. For Pearl, time even now is measured by accomplishment.

Pearl built her life around achievement and recognition and craves that still. Her identity began with the investment and strong determination to surpass her early roots: “Where I come from...the fact that I have no trace of that accent and that I can actually put an articulate sentence together is quite a sense of accomplishment for me.” Early in life, out of necessity Pearl embarked on a voyage to become dependable and strove to excel in everything she tackled. Work became the channel through which she forged her identity to become commander of her craft. Pearl spent years learning, developing, and mastering with fine tuned precision, a set of standards and procedures with which to conduct her life. With the diagnosis of terminal cancer, Pearl immediately drew upon her skills and “set her mind” to working on “a mission to die.” Failing to die and having to relinquish work because the effects of still living with a cancer that “you can’t control” has left Pearl floundering in uncertainty. Pearl is not in control, she “doesn’t get to say no to anything.” Pearl feels removed from a sense of normalcy and from living a life that is full of meaning where her values are endorsed and where she can gain respect from others. Pearl feels “duped” by her body and by the medical science she had learned to trust. The insidiousness of cancer fell below both her and her doctors’ radar. Cancer’s invasion of her body and into her world of knowledge and life’s work has threatened the integrity of Pearl’s entire existence. Unable to master knowing what will be the day to day effects of cancer, when it will interfere with her life, and when she will die, Pearl struggles with how to recognize herself in the experience. She “stands in her closet” at the threshold not knowing whether to turn towards death or towards life. The recurring failure of anti-cancer treatments, the physical distress of “profound fatigue” and a myriad of other disabling symptoms accompanied by emotional upheaval causes Pearl to doubt her worth and confidence in who she is and how to live in a world devoid of work. She has entered a world

where the randomness of cancer eclipses her scientific frame of mind. Pearl was very content in her life and was not looking for change she did not initiate. Her world was tidy and she “didn’t make mistakes.” Everything she did served a purpose and was ordered. Pearl likes being succinct and abhors incompetence. As a person who prides herself with applying high performance standards to everything she does, Pearl confronts the possibility of not getting this experience “right.” Paralyzed by wanting “everything done right,” the lived space narrows and further “restrains” her from living expansively or spontaneously while she is still able. She recoils from the unruliness of her emotions. She fears being stuck on a “pity-pot” and caught up in a web of emotionality. These reminders of vulnerability severely challenge Pearl’s self-image and diminish her sense of self-support, safety, and trust in this longer than expected situation that lacks all predictability and protocol.

Not finding the right way to live in the either/or world she has constructed indicates a moral dilemma which evokes ontological guilt. In relationship to others, Pearl wrestles with balancing how to take care of others with how to ultimately and fully give back to herself. She worries about whom she will be if she is not enough, how she compares to others and to her former “normal” self. Pearl has always been highly self-sufficient and is not “prepared” for the interference of outside factors that are beyond her control. With eroding self-sufficiency and diminished sense of trust in others, Pearl worries about being dependent upon others and does not want to burden family or friends. Careful to tread lightly on others “psychic spaces,” Pearl resumes her polished chief executive post and additionally assumes the role of protector in relation to others. Acting as health care administrator, interpreter, and provider Pearl gets to choose. She monitors the flow of information, tries to predict and modulate others’ affect, and places people in a hierarchal “three tiered model” for the

purposes of identifying to whom she can delegate tasks, deciding who needs to be taken care of, and who needs to be purged. She “identifies the criteria of how and who” can move within the model. She has found a way to have structure. Taking charge, shielding, and “shepherding” others helps Pearl feel more secure in the uncertainty of an ongoing terminal cancer. In relation to others in the face of dying, Pearl reaches for connection and pulls her immediate family members and friends closer. To offset the absence of family traditions she would have loved in her childhood, she creates family traditions and ritual to transcend her life. Pearl’s past successes and the interaction with others in the cancer world have brought her an “outpouring of friendship.” Through the supportiveness of these friends, Pearl regains some sense of her worth through the positive feedback of others who “verbalize what I mean to them.”

In the process of surviving longer with terminal cancer Pearl’s relation to others extends beyond her personal constructions and is additionally impacted by the broader social structure of culture. Cultural myths, expectations, and others’ attitudes further segregate Pearl from mainstream society. Cognitive and emotional dissonance results from other people thinking she will be “cured” because she looks “good” on the outside and from media’s attention on a pink ribbon cure. Pearl’s sense of isolation increases as does her need to mask emotions and protect family members from the cruel realities of her disease. Pearl’s urge then is to “educate and illuminate” the public and “clarify the misperceptions.” Undertaking this task would help Pearl fulfill her need to make a difference in the world and in turn give her a sense of belonging, to feel and be seen as a member of society worthy of esteem. But on most days, advanced cancer drains her of the energy this endeavor would entail. Alternatively, she turns to contributing through creativity. Pearl’s quilt making, at her own pace, becomes a



purposeful endeavor she derives meaning from in giving these hand made quilts to people she cares for:

Just that whenever I quilt or piece a quilt, whomever it is for, if I already know when I am making it who it is for, they are really in my meditation – it is a form of meditation for me – as I am sewing, the drone of the machine, the process, the project management of doing it, that person is in my consciousness. During that time I think of them, I wish them things and truly – I know this sounds so syrupy coming from me – but every stitch has some intention for these people. Sometimes I make a quilt because the colors or the pattern called to me, and I have no idea who it is for. I just start making it. Interestingly enough, by the time it is done, it knows who it belongs to.

In spite of the huge losses to her life as it was, Pearl remains “resilient” and perseveres. Pearl through ongoing treatment often comes in to contact with patients who have advanced cancer. Drawing on her “fortitude” to overcome obstacles and compelled to learn, she studies how others diagnosed with terminal cancer progress through life into death. Her thinking shifts into different paradigms as cancer continually rearranges her life. The most arduous aspect of this experience for Pearl is that change never ceases. There is no chance to settle, no gradual mastery and control over cancer’s progression and her demise. Pearl can’t confront the illness and have a chance to reorder her priorities and then get to move on, because illness becomes the priority and staying alive becomes more grueling and limiting. On days when Pearl is living well in her body, when the effects of cancer and treatment are not extreme, Pearl through yoga and meditation encounters moments of merging with a larger harmony and dying becomes more distant. On those days she finds meaning through creative endeavors, and she builds on the legacy she will leave behind. Pearl “stitches” a story that connects her family members of the previous generation to current and future generations. On those days, Pearl recognizes in which spheres she can exert influence over her life, make

meaning, have purpose, a sense of accomplishment, and reestablish her place in the world.

On the other days when the effects of having cancer are harsh and she is physically spent, Pearl is more bodily aware of death's approach. In her mind she has become familiar with the dying process, days of feeling good are on the decline and she expects to die. She becomes anxious about unfinished business and wonders has she done enough, has she done all she can. These are the days when suffering the dying process is feared more than death itself. Then those days pass, again. Pearl is unable to grasp fully how to do this life and death simultaneously, though she accepts death as a natural part of life. Pearl maintains hope, not for a cure but for an easier death, for what will be after death, and for her family and those dearest to her heart to eventually be comforted by the legacy she leaves. Contrary to the rules of science Pearl sees cancer play unfairly and finish in an "unclean death," yet she allows herself to fantasize and hope for a more surreal death scene of beauty and calm. Hoping for the best, living life as best she can, and preparing for the worst is the vessel upon which Pearl navigates the turbulence of cancer when she is not dry docked in the harbor.

### *Individual Textural-Structural Description*

The structural and textural elements of the experience are in a continual relationship according to Moustakas (1994). "It is the appearance and the hidden coming together to create a fullness to understand the essences of a phenomenon or an experience" (p.79). The next step in data analyses was to create a textural-structural description for each co-researcher. This description combines elements from the individual textural description and the individual

structural description. Jo's individual textural-structural description is presented as an example because unlike the other four co-researchers she presents as an anomaly. She has been living longer than expected with Stage IV cancer with no evidence of disease (NED) for five years. Unlike the other co-researchers Jo has not experienced the instability of ongoing recurrence and harsh treatments. Her situation therefore, highlights different aspects of the phenomenon.

How Jo experiences living past her expiration date and still living with a diagnosis of Stage IV cancer is directly related to having or not having evidence of cancer appear in cancer screening tests and to anti-cancer treatments. Jo's experience is situated temporally and spatially in relation to her internal process and in relation to others. Jo described her experience as changing over time. Over time, Jo's beliefs and ways of responding to her experience shift too. Jo described her experience by delineating three time phases on her cancer path: initial diagnosis; post diagnosis 18 months to 4 years later with NED; and in the current year. Part of what changes is her beliefs and how she subsequently decides "what things are important to you based on where you are on that path." When Jo was first diagnosed with breast cancer and metastases to her liver, she "bought into the diagnosis." At the time, Jo placed her trust in medical science and the experts who practiced the science. Resigned to die and hoping to live longer, she readied herself for the inevitable and followed conventional treatment protocols prescribed by her oncologist. Her doctors gave her not a specific expiration day but a range of time that left open the possibility for newer effective drugs to give her a longer span of time in which to delay death. With hope, the doctors also issued Jo a warning that cancer is known to outsmart most attempts to contain it. Looking at a truncated future, Jo experienced a really scary "dark period." Gone in the instant of diagnosis

were the life she had established and the dreams she had realized. The ground fell away from beneath her feet. Gone was the competent and self-assured person who had a successful and influential career. She had control over her life and the decisions she made had worked well for her, until now. The diagnosis was a signal that she was no longer in total control of her world. Jo began to look for ways to manage the tumultuous shock of cancer cells coursing through her bloodstream, eating her liver. The sudden awareness of her mortality, that “life might actually be shorter...might die and not live forever,” colored her nights black and left her standing alone, unsafe, and uncertain. As the fear of death and what she did not know about the dying process escalated, she busied herself with finding out as much as she could about her disease and death. Everything she read concurred or was even worse than her doctor’s prognosis. Confronting mortality is an ultimate test of aloneness and Jo began a frantic search for anyone who had her “exact diagnosis and was still alive” for more than one or two years. Her life now felt compressed with too much clutter and stress. Her life space became an uncomfortable fit. It was time to decide what was and what was no longer important. Jo began re-examining her priorities, hoping that newer treatments would buy her some more time. Hope was the desire for something positive to come out of the darkness, for a change that was difficult to obtain. Days slipped into months, a year, then 18 months elapsed and death did not call. Dawning was Jo’s realization that maybe you don’t have to die as early from cancer.

Having NED for more than a year using the same anti-cancer drugs, Jo still expected the disease to reappear but really thought that she could remain NED. She decided she would do whatever she could to stay alive. She embarked on a total remodel of her life. She quit her job, changed her diet, gave up her dream home, and with complimentary and alternative

remedies (CAM), “did it all.” For the next three years, Jo shifted from a position of resignation jumped past reconciliation and dove straight into remonstrating against the threat of death. She concentrated on long-term remission. During this time frame, Jo acknowledged to herself that the doctors did not know everything, were not the ultimate truth sayers, and were not experts on her life. Jo’s strong need to survive led her to doubt Western medicine’s ability to keep her safe and she took greater responsibility for her own recovery. From all cancer screening tests, it appeared that she was succeeding because she was “never expected to get into remission.” Remission for this long period of time allowed Jo to reestablish a sense of safety and faith that she could exert influence on how long she would stay alive. With cautious optimism, Jo believed that regaining control of how she lived and the decisions she made would work now as it once did before in her life. With NED there was once again the possibility for future plans. Jo’s confidence grew and she reordered her life story. Behind her actions, a question remained about why it was that she was still alive and others not. She wondered if she could she attribute NED to luck, conventional treatment, or to how she had changed her life and incorporated CAM. Jo witnessed metastatic cancer patients die and ruled out that NED could be attributed solely to conventional treatments. But she was not about to go off conventional anti-cancer drugs to test that out. Jo surmised that remaining NED must primarily be due to her willingness to do what others would not. Jo unlike her peers was ready to break away from the conventions she relied on in the past. She disdained the notion of luck and was annoyed with friends who said she was lucky. Luck depends upon randomness and lies beyond individual control. In contrast to the arbitrary and powerlessness of luck, is the omnipotent belief that if someone wants something bad enough and they try hard enough, they will get it. Jo felt that her lengthy remission resulted from all the changes and sacrifices

she made and how diligently she followed her CAM regimen. Jo remains frustrated with people who are more ill than she and who don't want to try CAM because she feels they are not claiming their power as she has done to beat cancer. Thinking of a friend that died from cancer, Jo believes if only she hadn't bought into her prognosis and if she would have tried "this stuff;" "maybe she didn't have to die from this diagnosis or maybe not in as short a time period as they had given her." Preventing or delaying mortality meant tying trust to some thing that appeared to have success rather than the uncertainty promised by the doctors. Reminders of others' vulnerability evoked a strong determination to conquer cancer, a psychological refuge from the overwhelming fear of death.

During these second through fourth years of surviving cancer, Jo attempted to "befriend death" to lessen her fear. Most of the activities she engaged in to conquer her fear were very short-lived. She trained for hospice but did not stay to work with patients for long. She thought about rocking babies in her spare time, thinking babies connect with the "special sparkles" they can see in her "aura." But the only opportunity that presented itself was with sick babies and Jo "just wasn't sure I could handle that." As the possibility of impending death receded further in her mind, Jo shifted her curiosity from the concrete aspects of dying to exploring ideas and others' opinions on life after death. In the process of dialoguing, she lost faith in the Catholicism of her childhood. Religious views blindly accepted were questioned. Jo described adopting a "new spirituality" to incorporate the existence of some form of life after death which in turn piqued her interest in developing her "psychic abilities." She felt no one else in the support group she attended was interested in discussing the topic of what happens after death and subsequently stopped regularly attending the group after several members died. Jo voiced feeling that she no longer fit, that she was "in a different place" and did "not want to

make any new friends with people who had Stage IV cancer.” The implication is that Jo feared their journey as too close to her own. She needed to escape to a space where she could feel more secure and at ease.

In the fifth and current year, as NED extends her time alive, Jo feels the threat of death from cancer to be less relevant in her current life. As cancer and death are no longer synonymous, death can be parked out of direct sight. Yet at the same time, Jo identifies herself as still living with Stage IV cancer and continues to be treated with conventional anti-cancer agents regularly, undergoes screening scans several times a year, and follows many CAM regimens specific to preventing cancer. Jo feels “totally confident” not only that she can remain in remission for a very long time, she also believes now that she is capable of curing her cancer: “if it can be done, I can do it.” A cure is not having to worry about cancer returning. Convinced that she will not die like others, she clings to the belief that she is different from others. She wants to believe she is the exception, “I lived longer with my type of cancer than anyone else.” “There’s no one else like me.” “It’s so easy for me, but I think I am the only one.” The mental sanctuary she establishes results in feeling more special and unfortunately far lonelier. Loneliness is painfully isolating. She feels there isn’t a place where she fits: “I’m in a different place than everyone else.” There is no space that conforms to her experience and no space where she can rest. With loneliness there is a sense of not belonging and feeling separate. Awareness that her experience sets her far apart from the mainstream of society and that her support group no longer meets her needs, she has no social network from which to obtain a sense of comfort, validation, and satisfying social contact. Loneliness is involuntary aloneness and invisibility. She feels bereft of others who can fully understand what it must be like to live with her experience and of feedback that gives her a sense of significance. “I guess I just don’t

feel like anybody gives any validation to what I do.” Loneliness then evokes self-doubt. Jo considers taking the risk of discontinuing one of her anti-cancer drugs to alleviate the side effects that impinge on her quality of life. After discussing this with her oncologist, she decided not to proceed with that choice. Uncertainty still abounds as to what is effectively keeping cancer from emerging again. Jo thinks she is “on to something,” and feels she is the “pioneer,” “explorer” and “pacesetter.” Jo perceives herself to be far beyond and outside the pack, “everyone I meet is behind me in diagnosis.” A pioneer ventures into unknown territory, the explorer searches out new information in that unknown area, and a pacesetter is the one everyone follows there. That is not quite Jo’s experience. Jo finds herself hunting for confirmation and support that someone has gone before her. She seeks validation from others, specifically with CAM, that it is indeed effective and that she is following the right course of action. Having experienced her world suddenly and unexpectedly turn upside down and inside out, Jo cannot completely and predictably trust her decisions or that cancer can be prevented or conquered without validation that there are others following her same path successfully. “I don’t know anyone who has done the things I have done with my same diagnosis and is not dead.” Experiencing a terminal diagnosis and having outlived her prognosis, Jo struggles with how she is going to connect with others and how she will figure out “Who am I now?” Loneliness engenders a sense of emptiness and hungers to make a difference in the lives of others.

In relegating cancer to the past and locating death far into the future, Jo finds herself in an identity crisis searching for her purpose in life. With NED for five years, Jo searches for what to do with a renewed sense that she can make future plans. She wants a purpose doing something that helps others. Jo though, pursues purpose with nonchalance. She doesn’t want



to put too much pressure on herself and have to “be doing something meaningful every minute.” Jo brings up the idea of purpose but stops short of making the exploration meaningful. She is concerned with what she can do and not how she can be. She avoids dwelling too long in her own depths to find meaning. To stop doing would involve moments of surrender, which is what Jo finds scary, and the opposite of what she believes she can gain from control. Fear is the driving force behind Jo’s search for everything that will help keep her alive and doing anything, meaningful or not, gives her purpose by keeping anxiety manageable.

Outliving one’s prognosis and still living with Stage IV cancer changes all the time for Jo and in the process of those changes she revels in being alive with no evidence of disease. Her confidence in staying alive longer is strong and she believes she has been influential in the outcome. The costs of staying alive involve changing her entire life, enduring continued anti-cancer treatment with side effects that at times impinge on her quality of life. The CAM treatments she chooses to vigorously adhere to receive little validation. She finds herself alone and lonely. Her experience being unusual in terms of mainstream society and from those diagnosed with metastases is isolating. Jo reaches out for companionship, for others who could confirm that one can control cancer, that life will not shatter again, and that she does not have to struggle alone in staying alive. Jo is unable to find companions who mirror what she hopes to see. Her strategies to avoid the fear of death may add to her estrangement from her self and others, which leaves her feeling ultimately alone. Lonely and with a renewed sense of a future, she searches for a purpose. Without finding meaning from which to act purposefully in the life she has endeavored to save, she is restless. She is looking for what is the next change in a world that appears to have more stability for her than it does her counterparts.

*Synthesis: Composite Textural-Structural Description*

The final step in analyses is to integrate the co-researchers' textural-structural descriptions into a composite. In this step, the textural themes, the concrete, and the structural elements, the abstract, are interwoven to create a final illustration of the core experience. This final synthesis captures the themes, the essences and meanings of the experiences of the group as a whole.

The co-researchers' experience of living past their expiration date and still living with Stage IV cancer was described as more than one experience and "always changing." How the phenomenon is experienced changes in the movement from the initial shock of diagnosis of metastases, to acknowledgement of their fate, to searching for how to live with their prognosis "in-between" life and death, as it too is in constant flux and laced with contradictions. Every aspect of the co-researchers' lives is affected by the changes terminal cancer brings. Being in the experience of all the changes is physically, psychologically (cognitive, emotional, and behavioral), socially, and spiritually complicated. How all this variability is perceived depends upon a complex of factors: the length of time co-researchers have survived with or without evidence of disease; the cancer trajectory, the range of metastases, and symptoms arising from disease and treatment; their unique set of beliefs and values that they bring to the experience; their relationships with others; and others' reactions to them. Being with the experience for each co-researcher changes "depending upon where you are on the path" in the multifaceted maze. The co-researchers are each "at different places with acceptance of what is to come and their management of the time in-between."

The core themes and essences that emerge from the study of these women's experience revolve around change. From the rich portrayal of what continues to change in living longer than expected and from the structures of how the co-researchers manage the constancy of those changes, the essences of the experience surface. The essences that emerge are the continuum of hidden suffering and the varying dimensions of fortitude that are experienced while living within a liminal space and time between life and death. The co-researchers experience suffering in the response to the threat of death, to ongoing disease in the body, and to endangerment to the integrity of the self. This suffering remains mostly hidden from public view. The continuum of suffering unfolds in the context of the co-researchers' struggles with the duality of their lives. The women in this study struggle to take responsibility for and participate in their health care and to make sense of what has threatened and continues to threaten their life. They struggle with a sense of belonging socially and with recognition of the self in the experience. Most of the co-researchers struggle to endure the chronicity of unpredictable and unrelenting disruption in their lives with changes to their bodies. The gamut of unremitting variability requires the co-researchers to repeatedly renovate their being-in-the-world while simultaneously living and dying. In the midst of suffering all the co-researchers hold onto hope and move with fortitude towards greater authenticity yet only a few of the women have obtained peace of mind.

The co-researchers began this "journey" of change when the awareness of mortality came like a "sledge hammer." The initial diagnosis of metastases was "shocking" because most of the co-researchers believed themselves to be safe having treated and survived early stage breast cancer a number of years previously. "I hit my five yard mark and thought ok, that's it...then all of a sudden" they were caught off guard. They lost their sense of place in the space

they once lived and lost how to see themselves in the world. For the co-researchers, being diagnosed with a terminal cancer is “overwhelming.” Being in the experience is having the rug pulled out from under your feet where you are thrown off balance and fall on an unforgiving, hard surface of the mortality of your life. The world as you thought you knew it and your preferred way of living become irrevocably altered. Gone are the delusions that if you are a good person or live a good life that you will be spared life’s hardships or live a long life. The women in this study feel betrayed by culture in regards to the subtle and not so subtle messages they received prior to diagnosis about work, health, personal achievement, and an expectable future. The experience feels like a betrayal of the body that was kept fit and followed treatment protocols but did not warn them. The body once lived in for protective shelter from deleterious elements has become a safe refuge for malignant tumors to grow. The body, the vehicle through which one experiences their whole life, maps the world as no longer safe or trustworthy. For the co-researcher, it feels like a betrayal with the medical system failing to prevent or detect disease sooner and still unable to identify the most effective treatment or determine how long you have left to live. Lived time and space no longer fit familiar expectations. The co-researchers’ previous thoughts and assumptions about how the world ought to be are useless in this new tumultuous and precarious panorama. In this sea of the unfamiliar, waves of ambiguity pound at their self-confidence and destabilize their sense of self-efficacy. What was once felt as orderly and ordinary is replaced with uncertainty and a swelling sense of “urgency” to figure out “what am I going to do?”

With death a reality rushing in the co-researchers found their senses flooded and needed to integrate this palpable awareness. Being women who were used to feeling “in control” of their lives, successful career women, “sturdy and resilient,” the co-researchers drew

on their skills and resources and dealt with the news by educating themselves. Learning all they could, the women began preparing for the worst case scenario while hoping for more life. Recognizing that once deceased they would no longer have the opportunity to choose how to live, many of the co-researchers felt compelled to decide how they wanted to be in death. Many began planning for their death. Preparing for some lowered the shock, helped to demystify death, and lessened their fear. Choosing to prepare and being able to state their wishes was to reassert their ability to have some control over what was forecasted. In their final moments they wanted to feel significant and complete. Most of the women desired a good death, to wrap up unfinished business, to relieve some of their perceived burden on loved ones, to depart from the world with a sense of dignity, and to leave a legacy. Not all the co-researchers prepared in this manner. One chose to contend the diagnosis with her “strong will,” “bargaining,” and whatever medical armaments were available. All the co-researchers endeavored to contain advanced cancer by choosing conventional treatments and believing Western medicine insufficient incorporated complimentary and alternative medicine/practices. Without exception at this time, the co-researchers, rather than ask why me, turned to ponder why not me and where do I go from here to face and accept the challenge.

Co-researchers accepted their fate, prepared to die or to do battle, and then didn’t die. Construction of the provisional structure each had designed to help them cope with imminent immortality was indefinitely delayed. The women gained a reprieve. They had discovered that a diagnosis of terminal cancer was not an immediate death sentence and that they could still live relatively well. It was death encountered, considered, and reconsidered and life deemed more precious. They “survived this thing that [they] were not supposed to,” and know that death is still “supposed to happen.” All the statistics and “experts” tell the women

they “should still expect to die” from cancer because there is no cure, but there is no definitive prediction of when this will occur, how fast or how slow. The co-researchers subsequently live suspended in this “in-between” liminal time and space, neither here nor there, in the twilight hours betwixt and between life and death. It is a “weird game” that is played where death “is there, but it is not right here,” “it is there, but yet you are not there.” In this “huge unknown,” experiencing time for these women is befuddling and time feels elusive. In this liminal space between life and death the co-researchers find themselves in cavernous disorientation with no “algorithms,” guideposts, or “role models” to supply illumination. There are no protocols for what to do, how to act, or who to be. The feeling is that “I don’t feel like I belong anywhere. I’m neither here nor there.” The threat of death “looms” large and ominously penetrates the confines of their life space. The lingering quality of death is felt as a heavy “burden” that is always “hanging over you” taunting and alienating you from yourself and from most everyone you know. “Knowing everyday that you are vulnerable, you are mortal...and feeling it” removes the co-researcher from the natural rhythm of day-to-day life and from those around them. The subjective reaction of the co-researchers is that they no longer feel they fit into society or that society fits them. Commingled with the threat of loss of life to death is the lost sense of belonging. It is feeling isolated in a world where “you are not like anybody else you know.” The co-researchers find people reluctant to talk about dying and the more frightening aspects of their disease. Instead others wanting to alleviate their own anxiety emphasize wanting them to be cured “as seen on television” and in the proliferation of pink for a cure. And myths get perpetuated: “Hardly anyone dies of breast cancer anymore.” When terminality is recognized, it is much easier for others to say “we are all going to die someday, it’s all part of life...enjoy it while you can” thereby negating the co-researchers’

overwhelming emotions and making communication about one's experience increasingly difficult. It is difficult for others to grasp the extent of their fears or the magnitude of danger of what it is like to be perched on the edge of life every minute of every single day. Being with the experience is to feel, without relief, the tension of perpetually living at the threshold of limited time not knowing the length of that time. Living in this space takes on textures of a "slippery slope" where any misstep feels "precipitous and dangerous" and where suffering remains concealed and the need for relatedness intensifies.

Painfully unable to share and/or have others understand the most pressing aspect of their lives is felt as a denial of their already threatened existence and contributes to the co-researchers sense of isolation and alienation. In turn, their intense want for others to understand "what it feels like to be me" grows exponentially. In the dichotomy of living and concurrently dying, there is the experience of looking great on the outside while unbeknownst to most others, being consumed on the inside with cancer cells and unable to explain fully or have others grasp the complexity of their circumstances. Trapped in a situation that is unprecedented, unpredictable, and beyond their control evokes suffering. These women's suffering often remains hidden from a culture where the people they encounter equate coping well with the co-researcher expressing a positive outlook and looking better than others expected. The co-researchers perceive most people unable to comprehend how it is to endure ongoing distress in the severe discomfort of cancer and anti-cancer treatments: "they don't understand me and I don't understand them." It is even more hurtful and denigrates their sense of dignity when others, especially medical professionals, treat them only as a dying person when they still feel and want to be still seen as vital. "If they thought I was a non-dying person, they would have worked hard, but I was just a throw-away. They were just like

palliating me. How dare they?” At the same time the co-researchers desire others to recognize the intricacies of their predicament they want to be seen as whole persons and not as a disease that others evade out of fear. The reaction of others toward the co-researchers engenders sadness, frustration and anger.

Many of the co-researchers were already versed in not expressing their emotions, so having to cloak their suffering increases the misery. It is the felt sense of “walking a tightrope” across a liminal space that is peppered with a “huge range of emotions” that fall “all over the map.” The co-researchers walk a fine balance between feeling their fears and sorrow and putting forward a best face, between feeling angry and masking their emotions to protect others from the threat of their reality at the expense of their needs. Their anger “without filters” is like a “seething cauldron” that rises to the surface to defend against the assaults on their bodies, against the threat of one’s sense of well-being, against feelings of vulnerability, and against the unfairness of it all. Against the lack of ability to control cancer, they feel powerless and become more determined. Some of the women are angry and confused that they have lived healthier lives than many of their peers and yet it is they who have metastatic cancer. They find it too difficult to interact with others who represent their own crushed aspirations. The women in this study feel like an anomaly being different from “breast cancer rookies,” “normal people,” and even from other patients with metastases. In the passionate wish for things to be different anger helps the co-researchers protect their sense of dignity. Yet because they perceive cancer as something they did not choose and have a diagnosis they can’t change, the expressions of anger are directed to targets that can be held accountable like “the stupid things people say,” the “idiot doctors” or loved ones who tell them “everything will be fine” “you won’t die.” The co-researchers were satisfied with the life they had. They are angry



in their belief they were already fine the way they were and that cancer didn't make them a better person, that having cancer "wasn't an epiphany for me." Some of the co-researchers blame organized religion and deity, and are angry at the lack of comfort "God's plan" has to offer them in their suffering. When their grief is not recognized and when expressing their anger appears socially unacceptable the co-researchers feel socially marginalized and unable to obtain the support they need. This experience intensifies their feelings of loneliness and estrangement. "It makes you feel even more lonely than others." The co-researchers sense of not belonging and fears of being abandoned compound the harshness of coming to terms with dying from terminal cancer.

Not all the co-researchers continue to be angry. Some of the women have "worked on letting anger go" and learned to let go of their "expectations of others." They are learning to recognize that the universe does not always appear rational and acquiesce to not being able "to predict the future or how you are going to feel." Many of the women in this study have become more assertive with their doctors and with how they guard their time. They are no longer silent doormats and there is no longer any opinion they don't feel compelled to share. They have become active decision makers in their health care earning the respect of their doctors. They now question giving their time and energy away to others to the detriment of the self, sensing the "line between self-care and selfishness." For some co-researchers, suffering through the biological growth of undifferentiated cells has led to discovering their indivisible wholeness. With everything they knew in question, one co-researcher finds herself in a process of individuation. In the process of "learning" to live with greater integrity combined with the recognition of a spiritual dimension she is able to reestablish faith in herself, gain dignity, and restore her sense of place in the universe. This co-researcher feels

cancer has given her the opportunity to find and make her life more meaningful. Aligned with her core strengths and beliefs, this co-researcher is less fearful and far more ready to take that “leap of faith” and risk stepping “off the edge” into the unknown, into “whatever that will be.”

The longer the co-researchers survive, the more their relationship with death changes. None of the co-researchers cling to death, some are waiting for death, and some have seized life. In living this experience death is not denied. The co-researchers accept the facts of the present diagnosis but it does not preclude hoping for *something* positive in the future. These women understand that hoping is within their influence but what they hope for lies beyond their control, will be difficult to obtain, and will always be accompanied by “the unknown.” Hoping is not wanting to die yet. Hoping is preferring possibility over probability. “I believe in the impossibilities;” there are exceptions and “I choose to believe it could be me.” For most of the co-researchers hope is not necessarily for a cure. What is hoped is for science to progress to give them more years, less distress, an easy death, and for their loved ones to be less burdened. Hoping is having a sense of ownership over their lives and spurs the co-researchers into active participation in their health care which in turn feels empowering, serves to strengthen their reserve and helps modulate suffering. Hoping sustains the co-researchers in facing death no matter what their view. For some of the co-researchers death is regarded as a natural part of the life cycle and they are comforted by the prospect of “life after death.” Some believe in the eternal essence of a person’s soul and/or a universal energy that transcends both life and death. Suffering is mitigated when these co-researchers are able to feel connected to a “universal benign loving energy” they believe cannot be destroyed. For some co-researchers

devoid of both a spiritual framework and feeling alienated from the larger culture, death is perceived as annihilation, and the anxiety that this generates must be fought against at any cost.

For the co-researcher who has no evidence of disease for several years, death feels more removed from the foreground and time appears to stretch longer. With NED the vantage point is different and the confines of space open as she believes in the certainty of a future with new possibilities to emerge. Although in this extended time, the space feels like a void where she is bereft of others with whom she can walk the same path or who could validate her experience. In the wideness of her search, she is unable to find a place where she has a sense of belonging or mutuality. For this co-researcher there are variations in how she experiences the phenomenon from those that live every day with evidence of disease. Recovering from the shock of diagnosis and prognosis and removed from experiencing recurrent/progressive disease, this co-researcher has the opportunity to integrate living with a terminal diagnosis with much less physical upheaval, greater physical capacity, and less frequent reminders of the impermanence of her life. This co-researcher's circumstances enable her to regain a sense of order and control in her world as she envisions a future she can plan. With a growing sense of self-efficacy she has the opportunity to reconstruct meaning to reconcile what happened to find purpose. It is different for most of the co-researchers whose upending circumstances do not stop changing long enough for them to find any sense of order and whose futures appear far less tenable. For most of these women each day has the feel of temporariness and they are tangibly aware of their mortality and feel their vulnerability through unremitting bodily reminders in the symptoms of cancer metastases and in the endless anti-cancer treatment effects they endure. For most of the co-researchers the future is foreshortened. Time is marked by episodes of tumor remission, recurrence, and progression.

Space is bounded by the limits of what medicine will be able to treat in their bodies. And the boundaries of the body are more keenly experienced.

With evidence of ongoing disease “you don’t know where you are in the process” in approaching death or what the quality of life will be from day to day on the way to death. The women watch others with a similar diagnosis die and wonder am I next? The unknown is more frightening than what is known. Uncertainty penetrates every crevice and incrementally chips away at their spirit. Being in the experience is “living knowing that you are dying” and dying while trying to live. For these women the fear of death becomes superseded by the fears of what they will “have to do to stay alive.” They fear not that they will die but about when and how they will die. They fear losing control, becoming a burden, being abandoned, becoming cognitively impaired, permanently disabled, and wracked with pain. Terminal cancer in this liminal space is not an illness where the co-researchers can encapsulate it, treat it, reorder their priorities, and move on with the rest of their lives. For most of the co-researchers treatment becomes “all consuming” and managing the symptoms becomes the central focus of their lives expending a great deal of their time. Time becomes a calendar of medical appointments and for the rest of their lives the body will be screened and medically charted. Their life space contracts even more as disease and treatment progressively impose greater physical limitations and incrementally and steadily limit their options for engaging in life. The failing integrity of the body causes greater psychological and social distress. For most of the co-researchers expecting to die is corroborated with how their bodies have become invaded by cancer and assaulted by innumerable medical intrusions. The co-researchers bodies have been slashed, burned and poisoned. The body once private has become a public target site for new drugs and procedures. The body hidden under wigs and clothing, stripped of hair, scarred, disfigured

with missing parts, disabled by neuropathy, nausea and bowel dysfunction, is now unfamiliar and one's sense of self feels alien. It is hard enough to absorb the threat of death let alone adapt to the massive changes in their physical capabilities that affect their quality of life and abridge their social roles. It messes with their self-image and self-esteem and they "have to work harder to feel good" about themselves. The burden and length of treatment often results in the co-researchers having to withdraw from their social roles. They struggle not to stay isolated. "Profound fatigue" absorbs their time, engulfs their bodies, and devours their lives. Fatigue inhibits the co-researchers capacity to have a fulfilling life. Fatigue interferes with their ability to engage in the simplest pleasures and leaves them without enough "personality" to socialize removing them further from others, escalating their isolation. Fatigue reduces the co-researchers' ability to adapt to emotional distress. Fatigue beyond the co-researchers' will to control is perceived at times as nonproductive and lazy when they don't even get out of their "jammies." "I get up and I stay up in my pajamas half the day and then it is time to go to bed again and I don't even change them. That is a whole new concept." In striking contrast to what they used to accomplish and how they used to be, and how they believe society expects them to be, suffering from fatigue is compounded by feeling misaligned with their own values. These women described short treatment reprieves or temporary remissions but never being able to trust again that this will last. For most of the co-researchers "it happens again" and they do not know each morning to what they will awake.

Most of the co-researchers experience living on an unending "roller coaster" erratically jarred between extremely "good days" and extremely "bad days." Time is encapsulated in the unsteadiness of illness that chronically changes between episodes of acute misery and intervals of respite. How the co-researchers describe good and bad days is

dependent upon how they feel physically which in turn directly affects their emotional well-being. Being in the experience is living in emotional contradiction between feeling wonderfully alive, grateful, and hopeful on good days contrasted on bad days with severe physical distress that leads to “profound sadness,” fear, guilt, anger, bitterness and sometimes despair. Time feels generative on the good days and deadly on the bad days. Good and bad days, either lasting days or months, determine the dimensions of time and space. “Some days I have a sense that I have a lot of years left. Other times I have a more narrow sense.” On bad days when “lying on the couch” in physical agony and feeling “no joy,” and “not wanting to do anything or see anybody” space closes in and dulls. On bad days, the many tangible and intangible losses incurred from having terminal cancer appear greater as physical functioning declines and interferes with every day functioning. The women are reminded that never again will they experience the “carefree ease of life” and may not have the ability to realize their dreams and goals. The body dying is acutely felt and death appears more imminent. The co-researchers worry about running out of treatment options, how much more chemo their bodies can handle, and losing total control over their quality of life. Suffering is affected by the co-researchers’ relationship to time and by their thoughts and beliefs. To think about their quality of life in the future is “scary” and for most of the co-researchers it increases their anguish. They try not to dwell in disappointment worried about descending into a “really big pity-pot” that will suck them dry and render them useless. They feel unlucky and worn down from all they have already gone through and will continue to endure. They ask themselves “how long will this go on, how much more will I tolerate?” On bad days when their quality of life feels completely vanquished, most of the co-researchers begin to consider when they might choose to stop treatment. They do not “want to continue if this is how it is going to be” and

their thoughts draw the end near. Shuttling back and forth between feeling good and feeling awful is mentally fatiguing and unsettling. “The biggest intrusion is being so tired of it all.” It becomes progressively “hard to just keep going on.” Some of the women are “tired of the struggle” of “fighting this battle I am not going to win” and “the worry about it all.” These co-researchers drained from having to do cancer are “sick of being a cancer patient” and “don’t want to be me anymore.” The physical distress has drained their psychological resources. Their thoughts engender tremendous guilt because they are “supposed to be so happy to be alive” and yet have “the audacity” to “feel that I just don’t want to do it again.” These women feel guilty complaining and feel guilty that they have survived longer than others without knowing how and they dare not tell anyone because “nobody would get it.” Experiencing again and again the loss of personal control, deterioration of the body, and quality of life bit by bit, the co-researchers confront the meaninglessness of the experience alone. Asking “why do I have to do this with my life” when “no matter what I do I am still going to die” is questioning how much more one can endure and the futility of physical and emotional suffering. They are searching for a way to make sense of their suffering and make that suffering more bearable. It steers the co-researcher towards a massive reevaluation of their priorities, deeply held beliefs, values, and expectations. They are trying to decide if they feel “lucky or unlucky.” The co-researchers find themselves questioning the meaning of one’s life and all existence. Directly confronting overwhelming feelings of loss, vulnerability, guilt, frustration, anger, and tremendous disappointment, takes fortitude and for most of the co-researchers is an opportunity to find meaning. They uncover meaning through self-discovery discerning “Why am I doing this? What am I doing this for?” Through the process of increasing their self-knowledge the co-researchers move towards authenticity. Authenticity is

finding congruency between their values and actions, to “know what I really believe” and to “make decisions from the heart.” It is discovering what is important and deciding to take time “now” for that which is indispensable. For these co-researchers, fulfilled with meaning is to find the “special treats out of the blackness” in being able to “give back to others,” in engaging in creative endeavors and finding a spiritual connection while accepting that their current situation “might not be how I would have chosen to be living.” “We haven’t chosen these diseases, but it is what we have.” Most of the co-researchers did not care about transformation, they were satisfied with the life they had. Being catapulted in to another “paradigm,” out of the necessity to cope they are groping to find ways to manage suffering. In the throwness of their circumstances they have all discovered choice. Each co-researcher is making decisions based on her individual viewpoint and moral “ethics” no matter how limited those choices become. Stopping treatment would result in death and for one co-researcher that is not her choice. Terminal cancer is not an option but how she deals with it is her choice. More than ever she is willing to accept any consequences because it truly is her choice. This co-researcher “would be willing to give up everything and everybody to grow old.”

On good days when the co-researchers are not bedridden and/or wracked with discomfort, the richness of life predominates and the space widens and lengthens. There is recognition that “not all the drugs are horrible” and they feel lucky to be alive with gratitude for times of doing things that they would have never done before. On good days time less constricted is free to embrace joy and fall in love with life. Life becomes more colorful and like roses full of scent opens to the promise of more days and more pleasure. For some, there is an opening to “flow” in to shared connectedness with the rhythm of the universe where they find “peace” of mind. Letting go into flow is to experience a sense of freedom that transcends the



body trapped by disease. Suffering eases with spiritual peace and connectedness, and one's condition is made more acceptable and a calm can prevail. When time is marked as a good day, the co-researchers consider everyone else around them with the same diagnosis to be worse off than they and death becomes more distant and somewhat less concrete. Life less "hard" becomes more spirited and imaginable. When the symptoms are less debilitating the co-researchers engage more actively in life and feel vivacious, even if it is half of what they used to do. Although none of the co-researchers feel cancer is a gift and are looking for the "return window," some of the women have found "the gifts in it." There is the "magic" of having more leisure time in which to travel and to share with loved ones and friends. On those good days one can "dance on the edge of a railing" and feel more secure. In connecting up with others the co-researchers feel less alone and more comfortable accepting their new and changing identities. On good days social relationships foster a sense of belonging and the women have greater capacity to feel themselves being in the world and not just peering at the outside of life. On these days, there is the vision of more options available for them to reach and the attitude of abundance versus scarcity is adopted. On these days one can live large. There is more time to salute the challenge of disease and renew determination. For some, on the good days the life space holds the potential for the development of the self and to bring out what was always there inside. "But you have to be off [anti-cancer] drugs to experience the transformation." On good days suffering is more bearable when life has meaning and the women are better able to face their limitations. In some moments, the intensity of suffering shifts and can appear to disappear. On these days there is greater appreciation for people and life and for making time and themselves a higher priority.

For most of the co-researchers, negotiating the severe highs and lows, twists and turns of terminal cancer, not dying and still expecting to die engenders cognitive dissonance and confusion as to how to proceed with life. The co-researchers struggle with how to cope and each woman manages differently based on her unique beliefs, values and strategies. Advanced cancer may not define them as a person, but it certainly restrains them in living. For most of the co-researchers it “interferes with the ability to have a life” they prefer. For some co-researchers terminal cancer required them to surrender their jobs. The space in which they could contribute and receive feedback from others that they were needed, wanted and mattered shrank. No longer able to work, some of the co-researchers are detached from opportunities that could provide them with feelings of competency and they are unable to continue satisfying relationships with their colleagues. The women struggle with a lost sense of identity and loss of meaning and purpose in life. Deprived of their social role some feel lonely. In a culture where work is considered mainstream and associated with being a respectful member of society, the co-researchers sense of not belonging and not being a person of value is intensified. With the loss of identity these co-researchers are in the process of revamping their perspective of time. As the number of years of survival increase, for some of the co-researchers, time free from the demands and stress of work is regarded as a “gift of time.” Forced unemployment for some co-researchers was welcomed time. Without work there was the opportunity to completely change their lifestyle. With not “having to try to cram it in before or after work,” there is time now to “figure things out,” “go for a walk anytime,” “turn on music and twirl around,” “meditate,” or just “sit” in stillness. When feeling good, there is time to volunteer and engage in helping others. Time subsequently becomes an investment infused with meaning in that the co-researchers try to decide how to best “spend” the time

they have left, how not to “waste time,” and how to “make time count.” Some co-researchers are learning how to “be” in time and live more fully in the moment and focus on joy.

For the other co-researchers who are able to stay employed, work is viewed as a distraction from the pervasiveness of cancer and a purposeful endeavor. On good days, one co-researcher is even able to return temporarily to her former work identity and is able to pick up a few consulting jobs as treatment side effects permit. To these women work signifies that they are still physically able and mentally capable to live more rather than less. However, work does not always assuage loneliness. Uncertainty still pervades and affects their relations to others at work. Working or not, all of the co-researchers living in liminality feel they are unique in believing that no one else has been through the same experience as they have.

For most of the co-researchers surviving longer than expected and still living with terminal disease feels like a “double edged sword.” It was being “told I had two years to live. Quits, travels, come back and then doesn’t die. OK, what do you do then?” Being in the experience makes it physically unrealistic and psychologically impossible to go back to how things once were and a total “conundrum” of how to live with expecting to die. For some of the co-researchers, living in the experience evokes a desperate search for the missing pieces of their past life. Like a jigsaw puzzle that was dumped upside down on the floor, they find instead that some of those pieces are forever lost, others irreparably damaged, and that the remaining pieces will never again fit back together to form the same whole picture. Not knowing time becomes psychically painful. It engenders fear and a sense of being lost. It is a loss of self, a loss of direction, and a loss of a sense of control. For some co-researchers the loss of continuity with one’s past and the loss of future plans, engulfs them in a state of

“limbo,” unable to move forward with time, unaware of how to live in the present time, and fearful that they won’t recognize the end of time. These women struggle with how to live day to day when life and death are no longer separate. They struggle with how to live when death feels surreal in those times when physical discomfort and symptoms of their cancer are absent or well tolerated. Some co-researchers desperately want an exact measurement of how much time remains so they can decide “what to do” with time. The desire to know the measure of time is the desire to make some semblance of order out of the chaos and to feel a sense of being rooted at least for a certain length of time. The co-researchers want to know how much time they have left so they can make a place for illness and keep the illness in its place for as long as possible. But this is impossible because “cancer is not something you can control” and “it has a mind of its own... its own agenda.” The co-researchers strive to take back control of their lives at the same time cancer is taking it away from them. When the co-researchers can find a way to incorporate cancer into their lives and not experience major changes in their level of functioning then still living with terminal disease is tolerable and life becomes enjoyable. But when the physical limitations diminish the scope of their life they find themselves desolately living around the impact of cancer, where “instead of it being the appetizer, [cancer] is moving to the main course.” To the co-researchers this means that cancer wins and they lose. It means that there will be no restoration to their sense of trust and safety. The experience feels “like quick sand.” There are no hand or footholds and “no matter what I do,” no matter how hard or how long the struggle, they will be swallowed up. The threat of becoming powerless with cancer taking over their bodies is stupefying and requires the co-researchers to dip deep into internal reserves they didn’t even know existed.

A few of the co-researchers somehow, just “deal with it” without their knowing how that occurs. Other co-researchers deal with the psychological fall-out by intentionally incorporating changes in their lives they believe will influence the course of their cancer and hang their hopes “on being the exception,” the one who survived longer. They are managing their suffering based on their beliefs, omnipotent or not, in sheer willpower, luck, hope, changes in lifestyle, expression of emotionality, and/or placing their faith in CAM to prolong their quality of life. All of the co-researchers cannot change the diagnosis, but what can change is how they decide to confront the situation and how they choose to behave and feel. Most of the co-researchers are aware that changing themselves does not guarantee a cure or a long life but it does ease the suffering and offers them more comfort in accepting the progression of disease and death’s inevitability. “Even though you still have all of those feelings, making a choice about it can make it more manageable.” To help them withstand the threat of death, cancer and treatment, the co-researchers utilize one or more sources of aid: a myriad of CAM practices; humor; pets; support groups; mood stabilizing drugs; helping others; advocacy; reexamining and rearranging their priorities; psychotherapy; the “outpouring of friendship;” the love of family members; a spiritual practice that incorporates meditation; and “dharma” discussions. Subsequently, they continue to live longer than expected with some exuberantly high times in between the more dismal periods. For some of the co-researchers though, time after time, year after years, dealing with recurrent/progressive disease takes a toll. These women have to keep working harder to find the mental fortitude to “do it again” and maintain their optimism. They “have to work harder to believe” that life still holds the promise of a reasonable and acceptable quality of life. Only two of the women feel that “the really good, wonderful times outweigh the really terrible times.”

In summary, the experience of living beyond one's expiration date and still living with Stage IV cancer is both unique to each co-researcher based on their beliefs, values, and actions and contains a kernel of all the other co-researchers' accounts of the phenomenon. For all the women in this study the experience is felt as paradoxical in every facet of their life and where the co-researchers themselves are a contradiction. They were supposed to die and they didn't. They have and continue to "beat the odds" in this relatively new phenomenon of living longer with dying. They may be the new statistics, but they are paying a high physical price for staying alive. The dichotomy of living and dying manifests in their experiences of good days and bad days with the good news that they are alive and the bad news that they get to live longer "lonelier than most." This requires the co-researchers to continuously readjust to living in a variable and incessant liminal time and space under the threat of death and enduring disease. The constancy of change impacts their lives often leaving the co-researchers feeling "like I don't fit anywhere" and feeling different from everybody else. With the losses "of chunks of the life and of your body that you loved" come new insights and a strong sense of agency in a situation that progressively limits their options. In the sea of uncertainty that surrounds them, exerting choice over what they can and surrendering to what they cannot control they discern their priorities and search for ways to put joy in their lives. Some women in moving away from the organized religion of their childhoods have found a spiritual connection, some entirely changed their lifestyle, some have gained deep inner awareness, and some women are angry and "profoundly sad." All the co-researchers defend against recurrent disappointments, new losses, and the "unknown" that awaits them. Many of the women are moving towards greater authenticity, connective and meaningful ways of being in the world. Although for most of the co-researchers, as the years of living longer with ongoing disease and

unrelenting and debilitating treatments persist, their resilience can be overshadowed by mental weariness and the sheer struggle to stay alive in a struggle that does not end.

## Summary, Conclusion, Implications

In the first section I provided an overview of the issues persons confront in living longer with advanced cancer. This section described the prevalence of cancer, the increasing numbers of persons surviving longer with cancer disease, and described their specific concerns. I addressed my interest in the topic, the purpose of the study, and posed the research question: What is the experience of living past one's expiration date and living with Stage IV cancer? In the second section I provided a review of literature of cancer biology and treatments, the psycho-social-spiritual impact of living with cancer, and palliative care. The third section described the transcendental phenomenological methods that were applied to approaching the study: the role of the researcher, the methods for collecting and analyzing the data, ethical considerations, protection of confidentiality, and strategies for validating the findings. The purpose of asking participants for an expressive representation of their experience was explained. The fourth section presented the findings of this study and discussed the emergent themes and the structural components of how the co-researchers experienced living and dying with terminal cancer longer than expected. This section concluded with weaving together the composite themes and structures into a synthesis. The synthesis elucidated the essences of the lived experience of the phenomenon. This fifth and final section will briefly summarize the study, compare the findings with the literature, review the limitations of this study, consider the implications for future research and clinical applications.



*Summary of the Study*

A review of the literature revealed little about the phenomenon of living longer than expected with terminal cancer. Most of the research about persons living with cancer focuses on earlier acute stages of cancer, survival issues after treatment ends, advanced cancer without a terminal diagnosis, or imminent death/end of life with terminal cancer. It is important to once again distinguish here that the use of the term “advanced cancer” in the literature refers to varying stages of cancer and did not always signify Stage IV cancer. The use of the term “terminal cancer” does connote Stage IV cancer and often imminent death. Only a handful of recent studies discuss the impact of terminal breast cancer on the lives of women who are living relatively well. There are a few studies that discuss research with participants who have miraculously survived cancer, are in total remission, and have terminated all conventional anti-cancer treatments. There is little published on the effects of living beyond one’s expected death and the psycho-social-spiritual aspects of still living with ongoing terminal metastases.

This gathering of data began with conducting in-depth open-ended interviews with five Caucasian women who are living past expected time with terminal breast cancer with varying degrees and sites of metastases. In the first interview, each co-researcher was asked to describe their experience in terms of the research question. This instruction was deliberately kept broad to allow for the greatest opportunity for the phenomenon to present itself without preconceived notions. This study attempted through the phenomenological methods of bracketing, phenomenological reduction, and imaginative variation, to vividly reveal the unique qualities and the shared essences of the lived experience of these five co-researchers. Each co-researcher’s individual situation and their responses to the circumstances, their thoughts, feelings and ideas, were explored. The inquiry did not seek causes or to explain why people are

diagnosed with terminal cancer, why they outlived their prognoses, or why it is they are still living longer with terminal cancer than expected. The aim of this study was to capture through the process of writing in multiple levels of increasing depth the complexity of the co-researchers' lived world in relation to the phenomenon. The five core themes that were described are: awareness of mortality; living on a roller coaster; feeling different from others; interaction with medical systems and treatment; cancer invades and changes how you live. The core essences that emerged from the experience revolve around the constancy of change and ever present dualities. The essences of this experience include living suspended in a liminal time and space between life and death, the continuum of hidden suffering in relation to the self and others, the dimensions of fortitude and preservation of hope. Fundamental to understanding these facets was how the co-researchers each struggle differently with a sense of control, a sense of belonging, and in finding meaning.

#### *Findings in Comparison to the Literature Review*

Several of the findings in my study are consistent with previous research. In looking at the biology of cancer, Brennan (2004), McGinnis (2002), and Moore (2004) reported that the same diagnosis of cancer manifests in the body differently across persons. This was found to be evident with the women in my study who all had the same diagnosis of breast cancer metastases but for whom the spread of cancer appeared in different areas of their bodies and with varying levels of severity. As a result of these differences, Turner (2005) found that when metastases was limited to the bones, involved no other organs, the patient could live a longer time. In my study the longest living co-researcher who spoke of outliving most everyone else she knew has had advanced cancer only in her bones for the last seven years. Chang et al.

(2006) and Holland et al. (2000) described the unrelenting and cumulative effects of cancer, treatment, and constant monitoring. The co-researchers in my study confirm this description.

Fatigue was reported as the most prevalent side effect of anti-cancer treatments and not successfully treated (Chang, et al., 2006; Lindstone, et al., 2003, Mock, 2001; Potter, 2004). Potter (2004) and Ferrell et al. (1996) reported that patients viewed their changing energy levels as a barometer of illness and regarded their decreased energy levels as a sign of recurrence or progression of disease. This was suggested in my study significantly when co-researchers experienced “bad days.”

Only one study (Goodwin, 2003), researching the concerns of ongoing disease in terminal cancer patients, discussed how patients’ stress was compounded by the threat of death. The co-researchers in my study all reported that the threat of death added to their levels of stress. Blank (2006) discussed the overwhelming nature of uncertainty and Potter’s (2004) findings suggest that greater frustration is experienced as a result of unpredictability. Butow (2002) reported that patients’ level of trust in their doctors diminishes in the face of prognostic uncertainty. Sales (1992) states that faith in the medical field decreases with recurrence and when treatments fail to contain metastases. These researchers’ findings were also evident in my study.

Literature distinguishes cancer as a biological disease from cancer as an illness that impacts multiple dimensions of a person’s life (Veatch et al., 2002). Research conducted by De Faye et al. (2006) on stress and coping in patients with advanced cancer has shown that the spread of cancer impacts every aspect of a person’s life. They reported that stress from cancer is multidimensional and may require different types of coping for different stressors. The descriptions of the co-researchers’ experience in my study demonstrated that cancer metastases

altered their lives physically, psychologically, socially, and for some spiritually. The findings from my study suggest that not only do the co-researchers' styles of coping differ depending upon what stressors they faced, their coping styles also related to their unique beliefs and strategies. The findings in my study also suggest that psychological styles of coping, positive attitude and/or fighting spirit alone, did not prevent recurrence across all co-researchers, which agrees with previous research reviewed by Petticrew et al. (2002). Subjective well-being was less associated with positive thinking and more correlated with finding meaning and resilience in a negative situation (Gotay, 2004). My study confirms these findings as well as those of Holland et al. ((2002) who stated that positive and negative feelings can change hourly in cancer patients depending upon the circumstances at the time.

Carter's (2003) study with advanced cancer patients reported that her participants were less afraid of death and struggled more with how to live in the face of death. Carter's research recognized that even though emerging themes were interconnected along the continuum of experience and could not easily be separated, having and using a sense of autonomy was the overriding factor that enabled the participants to cope best. In my study, having a sense of control and having choice was prevalent throughout the co-researchers' descriptions of how they adapted to change and how distress was better tolerated. Kissane et al. (2007) demonstrated that supportive expressive group therapy for women with metastatic disease enhanced their psychological and social well-being. For the woman in my study that spoke of regularly attending a support group, this was consistent with my findings in terms of her expressions of greater psychosocial well-being resulting from group interaction. However, one co-researcher in my study who rarely attended a support group expressed the greatest sense of well-being. My findings also showed that for some of the co-researchers that over the

long haul of having cancer care consume their life, they did not want to identify as a cancer patient and did not want to attend a group where this was the emphasis.

Baker (2005), Carter (2004), Rainbird (2005), and Turton (2000) concluded from their findings that patients with advanced breast cancer face different issues than those diagnosed with early stage breast cancer. The co-researchers in this study all spoke to the differences between themselves and early stage breast cancer patients. Accordingly to several researchers, Edelman (2000), Hammerlid et al. (1999), and Zabora et al. (2001) social and psychological distress in advanced cancer patients varied depending upon primary cancer site and the severity. The co-researchers in this study all had the same primary sites; however different levels of distress did appear in conjunction with severity. Although my study did not measure the effects of distress, the women described variance in the levels of distress across individuals that corresponded to the severity of cancer *and* the side effects of anti-cancer treatments. The level of distress described by the co-researchers in my study was dependent upon the level of pain, physical limitation, whether treatments were working or not, and the side effects of medications.

Kadan-Lottick et al. (2005) reported that as metastases worsened psychological distress increased. My study suggests the same findings. Kelly et al. (2006) found that psychological and emotional distress not only increased but could contribute to a diminished ability to connect with others, take away a sense of meaning, and have an overall negative effect on quality of life. As metastases worsened, the co-researchers in my study described struggling with a sense of meaning and most found their quality of life diminished.

In survey results, wanting information pertaining to quality of life was found to be the most endorsed item by cancer patients in the face of uncertainty (Hagerty et al., 2005). This

was corroborated in my findings with women wanting to know how much time they had left to live with quality of life. However, even though the women in my study had episodic inability to connect with others because of their physical symptoms, caused mostly by anti-cancer treatments, their lack of connection with others was more due to a sense of not belonging or fitting in with established social networks, having no role models, and feeling alien to the self and separate from others. Frank (1974) concluded in a general report on times of crisis that when distress mounts, often a person feels unique in believing that others have not ever gone through a similar experience cannot possibly understand them. All of the co-researchers in my study described feeling different from others and was described as compounding their distress.

Hope in cancer patients was reported as essential to psychological and emotional well-being in confronting ongoing disease and death, and hoping was not limited to the desire for a cure (Clayton, 2005; Ferrell et al. 2002; Maliski, 2003). The findings of my study concur with previous research. Having hope and finding meaning were reported to transform cancer patients' lives, to move them beyond surviving to thriving and to living more authentic lives (Benzein et al., 2001, Elliot et al., 2006, Winterling, et al., 2006). In response to the threat of death with cancer metastases, Arman et al. (2002) concluded those who claimed greater responsibility for living authentically, experienced life as more beautiful and meaningful. The experience of the co-researchers in my study suggests that they vacillate between surviving and thriving, living life the best they can and all move towards greater authenticity. However, transformation was described by only one woman in my study; only one co-researcher described appreciating life as more beautiful and meaningful than prior to diagnosis. My study suggests that psychological transformation in the face of terminal cancer remains inconclusive

in relationship to long-term survival with ongoing disease and unrelenting physical and psychosocial distress. Several researchers found that an existential crisis or at least existential distress accompanied a diagnosis of terminal cancer (Coyle, 2006; Hirai, 2003; Kelly, 2006; Kissane, 2002; Kissane et al., 2004). This is consistent with the co-researchers' experience described in my study.

In the HIV/AIDS literature, one study (Siemens, 2000) suggested that in coping with the crossroads of living with dying the participants were frightened by having to change their identity as a result of experiencing the double confrontation of not dying from their diagnosis and having to resume life with a different identity. The findings in my study suggest that the women were not frightened, but totally confounded by not dying when expected and struggle with how to live while still dying. In the few qualitative studies that were found addressing the concerns of women with breast cancer metastases, Armstrong-Coster (2004), Carter (2004), Davies et al. (2004) and Mitchell (2006), found that their participants experienced a loss of identity and all struggled with forming a new identity. Davies and Armstrong-Coster also described how the women in their studies felt different from others and experienced a sense of isolation. Armstrong-Coster reported that there was only one person in her study who lived past her predicted demise and experienced having to mask her negative feelings from others. My study supports and expands upon all of these findings. Arman et al.'s (2003) metasynthesis of nursing literature searched for how suffering in breast cancer patients was described. They found descriptions of suffering to be minimized; nursing literature tended to "pass over the darker sides of suffering to the change the process in a quick and easy jump" (p. 524). The experience of the women in my study described how the public's reluctance to acknowledge their suffering increased their psychological distress, decreased their self-esteem, and impacted

their dignity. My findings are consistent with Enes (2003), who in measuring the unmet needs of hospice patients found that dignity “meant more than being valued as a human being ...it related to having individual significance and to being a part of one’s own unique world...with a sense of competency” (p.268). Lack of dignity in this sense would be defined as persons perceiving themselves to be “incapable of dealing effectively with their stressful situation.” Each of the co-researchers in my study perceived themselves unable to deal effectively emotionally, psychologically, socially, or spiritually one time or another in different circumstances for varying lengths of time. However, the co-researchers in my study were also adept at handling stressful conditions at other times. Clarke and Kissane (2002) suggest from their research that these symptoms do not necessarily warrant a diagnosis of depression and describe instead “demoralization syndrome.” In the context of a severe threat “people suffer and become demoralized when they have lost or feel they are losing something critical to their sense of self” (p.738). Suffering grows with persistent and intrusive symptoms, the inability to find relief, the loss of hope that things will ever be different, in the loneliness of the experience, and/or in the patient’s expectations of other’s response to them as an ill person (p. 734-740). Many of the co-researchers in this study described many of these factors.

Bernstein (2001), Jones (2006), Mulkins et al. (2004), NCAM, 2006, and Shen (2002) report that due to individuals’ varied beliefs systems, there are increasing numbers of cancer patients who utilize CAM practices while continuing to receive conventional treatments. CAM is also reported to have the potential to increase their level of comfort and quality of life. These findings are similar to what was described in my study. My study additionally showed that for most of the co-researchers CAM was utilized because conventional treatments were believed to be insufficient. Spontaneous remission is considered in a few studies but does not



indicate if participants are still receiving conventional treatments to ward off recurrence (Gotay et al., 2004). What is not discussed in the CAM body of literature but surfaced in my study is the sense of not “fitting in” and feeling lonely when remission is long term and one is still diagnosed as terminal.

Anandarajah et al. (2001), Luoma (2004), and Wong (2002), report that most cancer patients, as part of their care, want spirituality be addressed. That was not consistently supported in my findings. In my study some of the co-researchers expressed not considering spirituality a part of their care but spirituality’s absence was keenly felt. Other co-researchers in my study described how spirituality gave them a greater sense of peace and feelings of connection with a transcendent power, which is congruent with previous research (Bowes et al., 2002; Giese-Davis et al., Greenstein et al., 2000; Laubmeier et al., 2004). Consistent with all the co-researchers in my study, Breitbart (2002) and Lin (2003) found that spirituality was not necessarily acquired through affiliation with an organized religion.

I have placed my study within the context of previous research and outlined where my findings were familiar, varied or dissimilar. There are no studies that specifically addressed the experience of living beyond one’s expiration date and still living with Stage IV cancer. The rarity of this phenomenon is changing as medicine is able to contain metastases longer now than ever before. With none of the co-researchers close to imminent death, my study drew attention to this particular dilemma. What my study brings to the foreground is the total conundrum of how to live with quality of life in the center of one’s dying, suspended in a liminal time and space, with no role models. My study highlights both the fortitude and the biopsychosocial suffering and spiritual challenge that results from the contradictions in the

constancy of change and the intensity of what persons with metastatic cancer have to do to stay alive.

### *Limitations of Research*

This was an exploratory study poised to penetrate the depths of the experience of a few participants. This study was limited to five women, too small a sample to make any generalized statements. This study most likely does not represent all of the multiple experiences that would be generated from a larger sample. Participants were self-selected from one geographic area. This factor in combination with not specifically recruiting any particular persons or accepting persons solely based on their demographics produced a less diverse sample. The demographics of this sample population were homogenous in gender, race, and socioeconomic level. The age range was 41 to 59 years and all the participants were diagnosed with the same primary cancer site. Additionally all the participants had attended the same drop-in support group for at least a few weeks. All of these demographics could have been influencing factors in their descriptions of their experience. Responses might differ if a more cross-cultural group of participants were interviewed.

All of the participants who self-selected agreed to find or create an expressive representation of their experience. It is likely that this requirement would limit participants who did not desire to express themselves in this manner. In this study, a few of the participants had difficulty completing the expressive project they chose because of new physical limitations that surfaced between times of data collection. This limited the additional non verbal research that could have been gathered. As rigorously as I attended to reporting

and validating the data as discussed in the methods section, my phenomenological description is only one possible perspective and is not exhaustive of other interpretations.

### *Future Research*

The experience of living past one's expiration date and still living with Stage IV has no role models. This phenomenological research documented both the unique and shared resilience and psychological toll experienced by a small group of women. Further research is needed to understand and provide psychological support for this growing population. This study elicited a broad range of responses from patients diagnosed with breast cancer metastases. Using the same methodology this study could be expanded by including more persons and/or more diverse populations in terms of culture, gender, age, and primary cancer site. More young adults are facing the challenges of cancer metastases and would have different challenges based on their developmental and family life cycle stages. The methods in this study were not focused on causality. By expanding the methodology future qualitative or quantitative research could focus specifically on any one of the issues brought to the forefront with this specific population: liminality, coping skills, hope, the sense of isolation/connection, agency, finding meaning or spirituality, role of CAM. To provide quality support for this population future research could incorporate the use and evaluation of specific interventions to ease suffering, enhance the quality of life. This research in turn, could help educate medical professionals with how best to serve the needs of this population.

Expanding out to the varied branches and orientations within the psychology field (ecopsychology, social, health, transpersonal/spiritual, feminist, family, or art psychologies) could reveal different dynamics of this phenomenon and engender greater understanding of

how to best serve the needs of persons experiencing this phenomenon. Future research need not be limited to one scientific field. There is limited oncology knowledge in the psychological literature and few psychologists have a knowledge base or skills to address these issues. Psycho-oncology research would greatly benefit from more cross-discipline studies.

### *Implications for Clinical Practice*

There is a dearth of information on psychological understanding or interventions for this population. To cope with surviving beyond expectations and living while dying from cancer is complex and diverse. As revealed in this study, there are no simplistic answers or one size fits all. The findings of this study suggest that it would be important for the psychologist to consider the totality of the experience. This study suggests that the patient be considered as a person with disease and not as a diseased person. It would be important for the clinician to grasp how difficult it is for the patient who has survived their death, and most likely for the psychologist, to hold the simultaneous and constantly shifting realities of living and dying that are not necessarily seen outwardly but are inwardly experienced. What this study indicates is that patients want to be “understood.” Being seen and understood as indicated by the findings of this study would require the clinician to examine his/her own anxieties with illness and death to be able to sit with patients, to listen to their suffering without rushing them to arrive at a positive outlook, and to honor their path when their outlook is positive and they dare not tread near suffering. Listening for the client’s strengths, beliefs and strategies and how they are experts on their lives is more important than deciding how they should or could best cope. It also means being comfortable in asking about death and dying and about what is most important in their lives. This research suggests that it might helpful to the patient, in hoping

for the best and preparing for the worst and dealing with the conundrum of time, to sort out their hopes and desires in terms of short, medium, and longer time intervals.

When considering symptoms of depression, it is crucial for the clinician to distinguish presenting physical symptoms (loss of appetite, fatigue, insomnia) that are usually associated with depression but are common to their medical conditions and not necessarily psychological determinants. Familiarity with screening assessments that are normed for medical illness would be beneficial. The most effective psychological approach would be multifaceted to best meet the needs of the whole patient. This might entail a combination of individual, couple, family, or group therapy as well as working as an interdisciplinary team member. Additionally, interpersonal approaches to therapy that encourage the oncology patient and their family members to develop a supportive social network could reduce isolation. From this study and previous research, dignity therapy, meaning-centered therapy, logotherapy, spiritual inventories, quality of life assessments, and expressive writing might be useful interventions. Gentle yoga, expressive arts therapies, and engaging in pleasurable pursuits, as they are physically able, could enhance their quality of life and provide patients with a sense of connection and meaning. Based on the data gathered in this study, effective psychological interventions would need to move back and forth between the medical, intrapsychic, interrelational, and existential worlds of the patient.

Clinical implications are not limited to the therapeutic encounter. Clarifying myths and increasing knowledge of the needs of oncology patients in public and professional circles are also the tasks of the psychologist. Endeavoring to be involved in research, publications, education, exchanging information across disciplines, and engaging in public policy discussions and decision making panels, psychologists can be change agents. This study suggests that

oncology patients would benefit from the advocacy effort of psychologists in the medical, social, financial, and legal arenas.

### *Concluding Remarks*

In this phenomenological study I attempted to provide a vivid portrayal of the themes, meanings, and essences of five co-researchers who survived beyond an expected time of death and who continue to live and die with terminal cancer. Each of these five women continues to blaze a path through a newer constellation of conditions as doctors and researchers are developing medicines with the promise of sustaining life longer, but unfortunately not cure cancer. Their stories are poignant and profound. They spoke with honesty, tears, and humor and I feel privileged to have been able to witness, listen, and reflect on their experience. My subjective experience of dwelling with the co-researchers and the data that were generated was also complex emotionally and academically. I had to continually remind myself to “come back to the things themselves” and fully engage in the process of Epoche. To complete this research I engaged in a non-verbal expressive process to represent a final intersubjective rendering of the co-researchers’ journeys through the maze of uncertainty and change. I created a series of Mandalas to represent my experience of the different moments of the co-researchers on their journey and the moments in which I was challenged in my attempts to capture in writing the themes, meaning, and essences of this phenomenon. (See Figure 8). The process of drawing these Mandalas also provided a protective container for my reactions of frustration, grief, disconnection, and fears in relation to their suffering. Through this self-supportive process of drawing, I could regain my centeredness and a sense of both the co-researchers and my own enduring spirit and was able to refrain from becoming

confluent with their experience or succumb to my own fears. Each of the following Mandalas represents a moment in time and space of my experience of the co-researchers' lived experience. My intersubjective experience continues to unfold and engenders new feelings and meanings as time passes.



Figure 8. Mandala Series



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## APPENDIX A

## INFORMED CONSENT

## INFORMED CONSENT

### Antioch University Seattle Informed Consent Form

The Psy.D. Program at Antioch University Seattle supports the practice and protection for human subjects participating in research related activities. The following information is provided so that you can decide whether you wish to participate in the present study. Please be aware that even if you agree to participate, you are free to withdraw at any time, and that if you withdraw from the study, you will not be subjected to reprimand or any other form of reproach.

*Procedures to be followed in the study, identification of any procedures that are experimental, and approximate time it will take to participate:*

I am being invited to participate in research that will explore the phenomenon of living past one's expected time of death and currently living with Stage IV cancer. I understand that the objective of this research is to elucidate detailed verbal descriptions and a symbolic expression of my thoughts, feelings, ideas, situations, of this particular phenomenon. I understand that the aim of this research is to illuminate the essences of the phenomenon as depicted by all the participants in the study.

My participation in this research involves the following procedures:

- (1) Complete a demographic questionnaire with a personally chosen or assigned a pseudonym.
- (2) Partake in an in-depth interview process. This private interview will be guided by Cynthia (Cyndi) Levine, a Licensed Mental Health Counselor (LMHC), Licensed Professional Counselor (LPC), and Nationally Certified Expressive Arts Therapist (CEAT), who is enrolled as a Clinical Psychology Doctoral student at



Antioch University Seattle. The interview will occur at a time that is agreed upon with the researcher at a site that is convenient for me. I will be asked to describe as completely as I can my experience of having lived past my expected time of death and currently living with Stage IV cancer. The interview process will be audio taped and, if I agree, video recorded. The audiotape will be later transcribed by a professional health transcriptionist who is bound by a confidentiality agreement and HIPPA laws. The transcription will remove all identifying information and substitute the matching pseudonym for my name. The video record will not be transcribed and its intended use is only for the researcher to check the accuracy of transcription. The interview will take approximately 40- 90 minutes. I will have the opportunity to review the verbal transcription in its entirety if I desire.

- (3) A follow-up email, fax, or face-to-face meeting that will last approximately 10-30 minutes will follow the initial interview to ask me to confirm, correct, and/or modify the researcher's written summary description of my experience.
- (4) I will be asked after this interview and summary review, to find or create through a form of visual art, poetry, music, or musical lyrics an expression of my experience of living past my expected time of death and currently living with Stage IV cancer. Art materials that I decide are needed will be provided to me by the researcher. I will work on my own on finding or creating this symbolic expression. The time this takes to complete (within the next three weeks) is at my discretion.
- (5) After finding or completing my creative expression, the researcher will schedule a meeting with me to share my symbolic material. At that time, I will be asked if I would like to share verbally anything about my expressive material. This meeting should last approximately 30 minutes. The verbal exchange will be audio recorded and subsequently transcribed. If I agree, this meeting will be video-

recorded. The video record will not be transcribed and its intended use is only for the researcher to check the accuracy of transcription and to be reminded of the expression I brought to the meeting. The researcher will take a photograph of my visual art or make a Xerox copy of my written expression or make a recording/duplication of my music. Inclusion of my expressive material (including any verbal exchange) in the final research document will be my choice. Any identifying information will be excluded. All original materials will be returned to me.

*Description of any attendant discomforts or other forms of risk involved for subjects taking part in the study:*

I understand that there are no direct risks to my physical health in participating in this study. I understand that the sensitivity of this topic and its personal nature might cause me to feel uncomfortable. If I become distressed and/or wish to discontinue the interview, I may do so at any time. Referrals to mental health professional cancer counselors will be available to me. I may also debrief with the researcher. I am aware that Cancer Care Resources (439 N. Broadway Ave., Portland, Oregon; 503-528-5236) offers no cost professional counseling services and assists persons with social service resources, all of which are available to me.

To protect my confidentiality, a pseudonym will be used to disguise my name. All data will be stored in a secure area with access granted only by the primary researcher and all data will be kept for a period of 7 years at which it will be destroyed.

I give my permission to be re-contacted at a later date for a possible follow-up future study:  
Yes \_\_\_\_ No \_\_\_\_

I give my permission for my records (no personal identification) to be made available as archival data for use in future related research. (If I check **No**, my records will be destroyed 7 years after completion of the study.) Yes \_\_\_\_ No \_\_\_\_

***Description of benefits to be expected from the study or research:***

I may not experience any direct benefit through my participation in this study, though I may find that having the opportunity to talk about and express my experience is personally meaningful to me. It is hoped that this study will contribute to the current literature about the experience of living past the time expected of one's death, and currently living with a diagnosis of Stage IV cancer. This study could contribute to both professional and public knowledge, increase understanding of this experience, and foster future research and development of more comprehensive and sensitive treatment options.

***Appropriate alternative procedures that would be advantageous for the subject:***

Since this is an exploratory study and does not involve mental or physical health treatment, there are no alternative treatments. Related resources in the community will be made available to me if requested. There is no monetary compensation for my participation, though I may request a relaxation/visualization audio recording and/or a written packet of meditative scripts that are available to me at no cost.

I have read the above statements and have been fully informed about the nature of this study and the procedures used in this project. I have been given sufficient opportunity to ask any questions I have concerning the procedures and possible risks involved. I understand the potential risks involved and I assume them voluntarily. I likewise understand that I can withdraw from the study at any time without being subjected to reproach. I may also ask for a summary of the results of this study.

**Subject's signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**Researcher's signature** \_\_\_\_\_ **Date** \_\_\_\_\_

## APPENDIX B

## DEMOGRAPHICS INFORMATION FORM

## DEMOGRAPHICS INFORMATION FORM

Name \_\_\_\_\_ Age \_\_\_\_\_

Gender \_\_\_\_\_ Religious Affiliation, if any \_\_\_\_\_

Ethnicity \_\_\_\_\_ (e.g. identify with Asian, South Asian, Pacific Islander, Latino, African-American, Arab, Middle Eastern Heritage, etc. or self-described Other)

National Origin \_\_\_\_\_ (e.g. immigrants, refugees, international students, etc.)

Indigenous Heritage \_\_\_\_\_ (e.g. North American Native American Indians, Alaskan Native, Native Hawaiian, Samoans, etc.)

Highest level of education received \_\_\_\_\_

Please circle one of the following:

Single      Married      Divorced      Legal Union      Have Significant Partner

Socio-Economic status \_\_\_\_\_ (e.g. status by occupation, income, rural, or urban habitat)

Site of Original Cancer \_\_\_\_\_ Current Prognosis \_\_\_\_\_

Current sites/type of cancer:

Please list current treatments:

## APPENDIX C

### INITIAL INTERVIEW SCREENING GUIDELINE

## INITIAL SCREENING INTERVIEW GUIDELINE

Thank You for your interest in this research project. I am Cyndi Levine, a doctoral student at Antioch University Seattle. I am doing research for my dissertation on the experience of living past one's expected time of death and currently living with Stage IV cancer. I have heard from many women that they would like to share their experience in hopes of promoting awareness and gaining greater understanding from other health care professionals, family and friends, and for themselves.

May I ask you a few questions to see if this study is a good fit for you?

Please be assured that you may choose not to answer any question and to end this conversation at any time. Your participation is voluntary.

Are you over the age of 18 years?

I am looking for people who have lived beyond a period they expected to die and are currently living with Stage IV cancer. Is this your experience? If the response is yes ask, "What factors gave you that expectation?"

If the response is No, Stop and respond with "Thank You very much for your interest. I am sorry that your experience does not match the experience that I am hoping to find for participation in this particular study."

If the response is yes, continue with the following questions:

I will be asking you questions of a personal and sensitive nature about your cancer experience. Are you willing to respond or do you have any concerns about talking about these sensitive issues?

Could you briefly tell me about what type of cancer you have?

In what areas of your body has cancer metastasized?

Do you have any questions or concerns about any aspect of this project?

Thank You for your interest and willingness to talk with me today, that's all I want to ask you at this time.

If the prospective participant is unable or decides not to respond, has concerns that cannot be addressed add to the above statement, I believe this study might cause too much discomfort for you and would not be a good fit. Thank you again, for contacting me.

If the potential participant is appropriate for this research proceed with additional information about the procedures of the study and if possible, schedule a time for completing the informed consent, demographic questionnaire, and an in-depth interview.



## APPENDIX D

### INTERVIEW GUIDELINE: CLARIFYING QUESTIONS

## INTERVIEW GUIDELINE: CLARIFYING QUESTIONS

Could you describe that in more detail?

What were you aware of in that situation?

What was that like?

How did that happen?

Could you tell me more about that?

I'm beginning to get the picture, could you say more?

I'm not sure I understood what you meant by that, please let me repeat to you what I think you said and please correct or elaborate on that?

## APPENDIX E

## SIMONE'S EXPRESSIVE REPRESENTATION STATEMENTS

Simone's Expressive Representation Statements

**The Metastatic Breast Cancer People**

My family and friends don't understand.

I don't feel like this new treatment will work.

I just found out I'm metastatic. I don't want to do treatment. Chemo is so awful and they say I'll be dead within 2 years so why bother.

I'm tired all the time.

The chemo is not working.

I'm going on hospice.

I'm switching to another chemo because I can't stand the side effects of this one.

So far my treatment is working...

The tumors in my liver are shrinking slowly.

I'm on my last possible treatment. If it doesn't work,...

I planned my own memorial service. It's comforting.

I have lived with metastatic breast cancer for 3 years.

**ME**

They always say deaths were "peaceful." Like that is supposed to make us feel better about losing a friend FOREVER. Just once, I would like the announcement to say "the last thing she said was spit in my eye" or "we had to hold her down because she was kicking and screaming" or "her last words were I'll see you all in hell." When I die, I'm going to have them put something like that in the obituary just to see who's paying attention.

I don't want to be ME anymore.

When people die, other people say they **passed**. Passed what? But what I really want to know is: did they collect \$200.

THIS is bullshit.

I'm SO LUCKY that I get to see my friends die one by one.

THIS is part of the PLAN? Can we go with Plan B?

Am I in denial?

I don't feel like I belong anywhere. I'm neither here nor there.

I'm scared. Who do I talk to?

This is an OUTRAGE!

Why is it ALWAYS a BUS?

A few people have been cured of metastatic breast cancer. However improbable, it's POSSIBLE.

WHY am I brave? I either fight, give up, or kill myself. I'm not brave.

Even after 11 ½ years, I REFUSE to ACCEPT this cancer!

Am I LUCKY or UNLUCKY?

Hell NO. I won't go.

Death is the New Black

Who am I kidding? Who do I know who has lived even 20 years with metastatic breast cancer?

I'd give up everything and everybody else in my life if it meant I could grow old with Jeff.

I'm always afraid.

My sadness at the death of my friends is so great sometimes I think I can't bear it.

I found some long-term survivors of metastatic BC. If they can do it, I think I can too.

Obituaries often say the deceased fought a long, brave battle with cancer. How come it's NEVER a short, cowardly skirmish?

### **The Normal People**

Your clear PET scan means you're cured, **right**?

Hardly anyone dies of breast cancer anymore.

You know, any one of us could step off a curb, get hit by a bus, and die tomorrow.

You're so brave.

You'll be fine.

When you die, you can ask God and Jesus why this happened to you. Until then, just accept that there's a reason.

God doesn't give you more than you can handle.

You're an inspiration.

You must be super happy that you aren't on treatment anymore.

I knew a young woman who had the same kind of cancer as you. She's dead.

Lance did it.

Is your treatment working?

Your cancer is all part of God's plan.

Well, if you're going to die soon you should start acting happier. If you don't you're going to ruin the rest of your life.

But you're okay now, **right?**

When will you be finished with your treatment?

You'll beat this because you have a great attitude.

So things are back to normal now, **right?**

Just keep a positive attitude.

Let's buy a bunch of pink M&M's so we can CURE breast cancer!

It must be fun to wear a wig. You can try all kinds of new looks!

How ARE you?

My grandmother had breast cancer 50 years ago.

Just keep the positive attitude.

### **The Early-Stage Breast Cancer People**

You know, breast cancer is more deadly in younger women.

I was really scared at first. But my Sisters in Pink inspired me to be a survivor.

Breast cancer is the best thing that ever happened to me. It taught me to appreciate my life.

We've been through SO much.

If I ever feel scared, I always have another survivor who is further down the road that I can talk to.

Weren't you getting regular mammograms?

WE'RE survivors!

I didn't have ANY positive lymph nodes.

I'm cancer-free!

I got MY cancer detected early

These pink bracelets show our dedication to the cause.

I know my positive attitude is what saved my life.

I've been through HELL: a lumpectomy, 3 grueling months of chemo, and 7 horrible weeks of radiation.

It's fun to give each other pink earrings!

You're not STILL on chemo, are?

How many positive lymph nodes did YOU have?

When you've had breast cancer, you are bonded forever in a sisterhood.