

UNDERSTANDING THE EXPERIENCES BREAST CANCER: A OF STAGE IV
QUALITATIVE INQUIRY OF A STAGE IV DIAGNOSIS

By

Karly J. Downs

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ABSTRACT

UNDERSTANDING THE EXPERIENCES OF STAGE IV BREAST CANCER: A QUALITATIVE INQUIRY OF WOMEN WITH A STAGE IV BREAST CANCER DIAGNOSIS

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Karly J. Downs

Women with Stage IV breast cancer face a multitude of stressors associated with treatments, illness, mortality, and creating a quality life. The current study examines a sample of 10 women from across the United States, who are living with diagnosed Stage IV breast cancer. Through the combination of two theories, comprehensive task model and relational understanding of life and death, a set of semi-structured individual interview questions were created to assess the multifaceted experience of living with this diagnosis. The purpose of the interviews was to capture the lived experiences of the women, gain an understanding of what adds to and takes away from creating an optimal quality of life, and to gain an understanding of the needs of this population throughout their experience. A phenomenological analysis approach was utilized and a conceptual model of quality of life and needs is presented. Results show that making meaning through relationships, faith, and finding purpose in life were the major factors in creating quality of life and body deterioration and financial stress were the major themes that took away from life quality. Additionally, personal characteristics and Stage IV specific characteristics were also important within the experience. Connection and education were the two identified needs of this sample. Clinical implications, limitations, and future research are presented.

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I dedicate this thesis to my family. First to my husband, my partner in life, my rock, Dr. Adam Downs. You have helped me in every way to become the person I am today and to accomplish so many goals in my life. Second, to my daughter Harper Jo Downs. I hope to be a constant inspiration in your life. Your strength inspires me daily. And finally, to my mother, Kathy Redburn, my father, Jack Redburn and my sister, Dr. Danielle Redburn-Whittle. I love you all very much. Thank you for the journey that has led me to such success. You have all help me to become the person I am and have been a constant support in my educational goals. Thank you for always being there for me.

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CHAPTER 1: INTRODUCTION

Background of the Problem

A diagnosis of breast cancer is complex with many variations within the illness. Breast cancer has eight main classifications or stages. As stages increase, the severity of the disease increases exponentially with Stage 0 been the mildest form and Stage IV incurable. The staging system was created by the American Joint Committee on Cancer to provide a strategy designed to group patients based on prognosis. When a diagnosis is made, stage is determined by examining tumor size, lymph node status, estrogen-receptor and progesterone-receptor levels in the tumor tissue, human epidermal growth factor receptor 2 status, menopausal status, and the general health of the patient (Singletary, et al., 2003) (see Appendix A for table of Stage specifications). There are several differences that can be observed between each stage of breast cancer. However, a diagnosis of stage IV breast cancer is the only stage where a distant metastasis is found. The occurrence of a distant metastasis is defined as the spread of cancer from the primary tumor or lymph nodes to another area of the body. Commonly, breast cancer will metastasize in distant lymph nodes, bones, liver, lungs, or brain, but can spread to anywhere within the body (American Cancer Society, 2011). Women diagnosed with breast cancer may also develop or progress from a lower stage diagnosis to a Stage IV status when evidence of the spread of cancer is found.

In 2013, 232,340 women were diagnosed with invasive breast cancer, compared to 64,640 diagnoses of in situ breast cancer or cancer confined to the original location where the cancer developed (American Cancer Society, 2013). Invasive breast cancer is defined as cancer that has broken through the glandular wall where it originated and grows in surrounding breast

tissue. More specifically approximately 6% of women diagnosed with breast cancer will eventually present with a Stage IV diagnosis (Surveillance, Epidemiology, and End Results Program, 2007). When a woman is diagnosed as Stage IV, by definition, the prognosis is poor. A poor prognosis refers to the high mortality rate and a limited length of life. Among those diagnosed with stage IV (breast cancer that includes distant metastases), 24% of the population will survive up to 5 years as compared to 99% of women with localized breast cancer (American Cancer Society, 2013). Other studies have shown that from the time of diagnosis, women will have an average survival rate of 2-4 years (Hortobagyi, 2002; Williams & Buchanan, 1982). These findings indicate that a stage IV diagnosis leaves women with a strong sense of mortality and diminished hope for the future.

Women with this diagnosis have a multitude of treatments available (e.g. hormone therapy, drug therapy, chemotherapy, mastectomy, or oophorectomy) and combinations of treatments are typically utilized. Unfortunately, there is no known treatment, nor combination of treatments that has been found to cure established Stage IV breast cancer (Chunleestkul, Carlson, Koopmans, & Angen, 2008). Although a cure has not been found, recent research has examined whether specific medical treatments improve survival at the level of Stage IV (Dominici, et al., 2011). When examining the use of surgery to remove the primary tumor where cancer originated, no improvements were found with a sample of 551 patients with diagnosed Stage IV breast cancer. The mean of survival for treatment versus control were 3.4 years and 3.5 years respectively. These types of findings illustrate the severity of the development of metastatic breast cancer.

Curability of metastatic breast cancer is difficult to define. When is the cancer considered to be “cured”, is a question that many researchers struggle with. Stage IV breast cancer is difficult to treat with rate of survival the ultimate outcome as opposed to cancer remission that can be seen in other stages of breast cancer (Chunlestsikul, et al., 2008). In a review of several studies examining the effects of systemic treatments for limited metastases (cancer that has spread only to the regional lymph nodes and not to other areas in the body), some treatments have been found to be beneficial in increasing the survival rate with 3%-30% of women included in studies having found a “personal cure” or a combination of treatments that increase their survival between 5 and 20 years (Hortobagyi, 2002). This wide variation in survival time is dependent on many variables including age, health of the individual, treatments utilized, and the like.

Women with stage IV breast cancer have many psychological needs and concerns when compared to other stages of cancer. Breast cancer that has spread leaves women with no option of a cure, but with the need for systemic treatments that can cause pain, discomfort, anxiety, and depression. Additionally, thoughts of mortality and the limitation of life are evident for this population. Due to these factors, the psychological needs of this group of women is great, as fears and anxieties around health and dying are severe (Classen, Koopman, Angell, & Spiegel, 1996). For many of these women, surviving cancer or celebrating the idea of being a cancer survivor is not a part of their story due to the high level of mortality and limited life expectancy. This creates difficulties in that these women may be reluctant to reach out to the breast cancer community where there is a great focus on survival and “beating” cancer. Women with a Stage IV diagnosis likely will not spend another day in their lives without cancer and in fact, most have limited time left to live.

One study of 66 women newly diagnosed with stage IV breast cancer examined their levels of distress. Physical and psychological symptoms were assessed through self-report questionnaire. Women commonly reported feelings of sadness, lack of energy, sweats, feeling irritable, coughing, feeling nervous, lack of appetite, dry mouth, and pain. In this study, semi-structured qualitative interviews were also utilized to further assess the reaction to this diagnosis. Women reported that uncertainty, anger, lack of communication with doctors, worry for family, and stress were frequently experienced (Turner, Kelly, Swanson, Allison, & Wetzig, 2005). The combination of multiple stressors can lead to difficulties physically and psychologically, but can also influence the quality of life that these women experience.

Increasing quality of life and addressing unmet needs of women with late stage breast cancer are key factors in helping this population (Aranda, Schofield, Weih, Yates, Milne, Faulkner, & Voudouris, 2005). Quality of life and health related quality of life have been examined within the literature specific to this population. In an examination of 361 women representing all stage classification of breast cancer, women with metastatic breast cancer are found to have the lowest rates of health related quality of life (Lidgren, Wilking, Jonsson, & Rehnberg, 2007) as defined by five dimensions; mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Quality of life specific to symptom severity and physical functioning has also been examined, with women with non-metastatic breast cancer experiencing better quality of life than those with metastatic breast cancer (Siddiqui, Given, Given, & Sikorskii, 2009).

Quality of life concerns have developed into a wide variety of needs and psychological distresses for this population. A study of 105 urban women, with metastatic breast cancer, were

examined to assess the quality of life and needs of women living with this form of cancer. Overwhelmingly the most common unmet need for this sample was psychological and health related information. Specifically, worries about loved ones, uncertainty about the future, fears about physical disability or deterioration, and information on how to find help related to the illness were the most commonly reported needs (Aranda, et al., 2005). Even though this is a severe form of cancer, the literature has large gaps, especially when it comes to the emotional and psychological wellbeing of this group and how they are able to maintain an optimal quality of life in the face of this diagnosis. Musa Mayor, founder of the advocacy for advanced breast cancer (AdvancedBC.org) explains the need in an article written for www.breastcancer.org (Fiore, 2009), "Women with metastatic breast cancer are a neglected community. By that I don't mean they receive inferior medical care, but their psychosocial and informational needs are often not very well met."

Purpose of Study

This study adds to the understanding of women living with stage IV breast cancer, their experiences with cancer, how these women are managing their lives, and what they do or desire to have in order to live with an optimal quality of life in the face of such a demoralizing diagnosis. Gaining an understanding from those who live each day with this disease is of importance in order to create and enhance existing educational and therapeutic treatments for women in this situation.

The findings from this study will inform future interventions with women with Stage IV breast cancer. For example, the group treatment literature for women with breast cancer does not clearly differentiate the specific needs and difficulties that women with Stage IV cancer face

compared to those with Stage 0-III. Instead, most of the efficacy research specific to psychoeducational and supportive group treatments either exclude women with such a severe stage of breast cancer or they are included in a general group of women with all stages. Understanding the unique situation of these women will expand the breast cancer literature, inform those who are currently conducting psychosocial treatments for women living with Stage IV breast cancer, and provide insights into what needs to be added to current interventions specific to this population. Additionally, this research will help to inform research and practice on ways to address the relational needs of this population by assessing how family and community influence the quality of life of these women. To date there is no research specific to the family relationships and how they influence quality of life for women with a Stage IV diagnosis. The current research will shed light on the role that family and community plays within this disease.

Theoretical Framework Guiding the Study

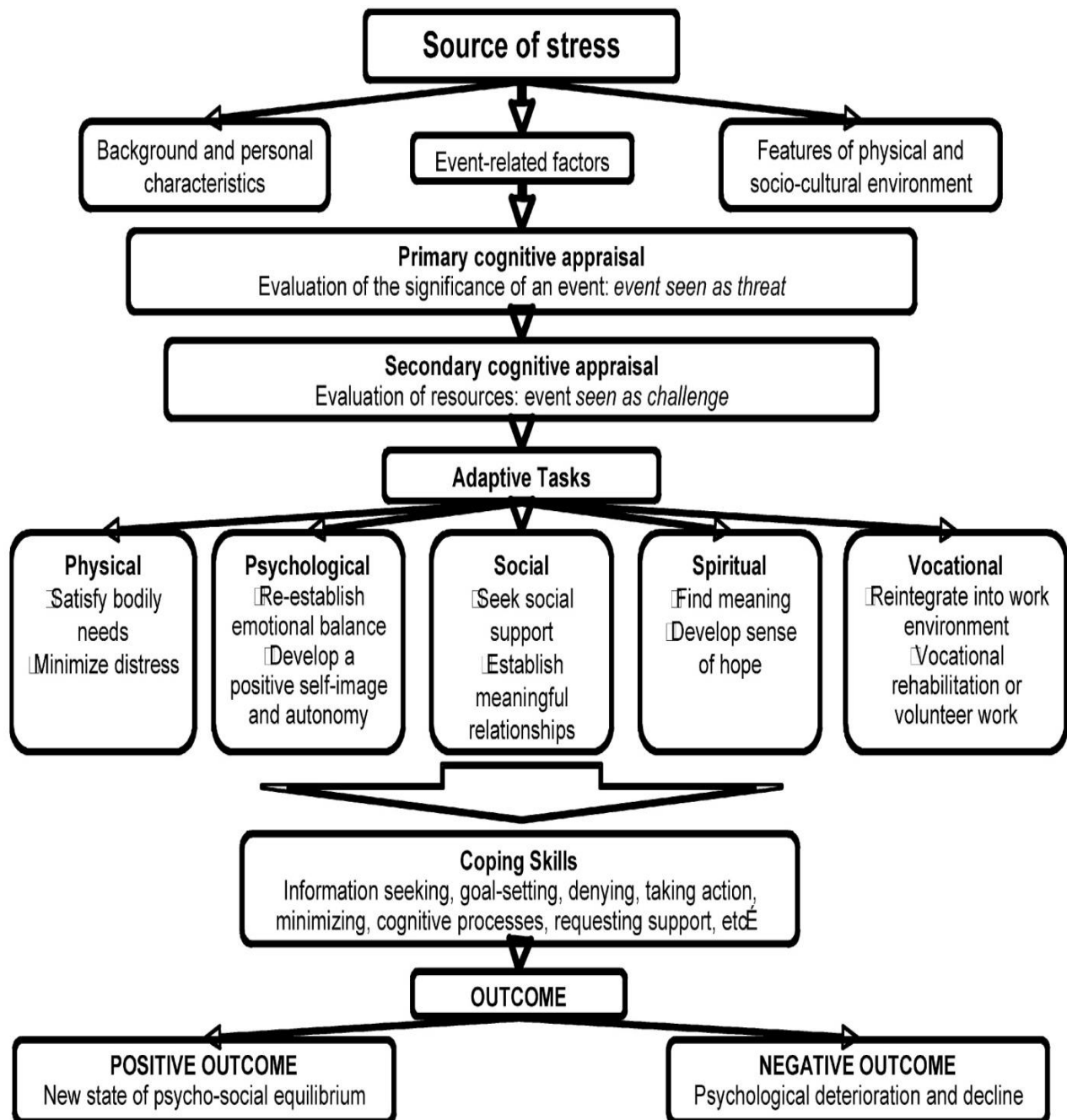
This study will utilize two theories that will guide the research questions. The “comprehensive task-model approach” to coping with a chronic illness (Samson, & Siam, 2008) will be the base for the theoretical model with the “relational understanding of life and death” (Wright, 2003) as an additional perspective to increase the understanding of the influence that death has on an individual. The process of coping with a terminal illness and facing mortality is a key factor in understanding the experiences and needs of a population of women with Stage IV, terminal breast cancer.

Comprehensive task-model approach. Samson and Siam (2008) began their work by identifying two paradigms that exist in the literature on coping with death and dying; stage

paradigms and task based paradigms. Stage based models (e.g. Kubler-Ross, 1969) have been historically criticized for the linearity and limitation to individual variations. The task based paradigm represents a more fluid approach that focuses on tasks to be accomplished as opposed to stages. Samson and Siam (2008) embraced the paradigm of tasks due to its focus on reconstructing a persons' existence in the process of adapting to a terminal illness.

A task has been previously defined by Corr (1992) as work that must be completed by those coping with mortality with an outcome of reconstructing a specific aspect of life that is affected by chronic illness. Samson and Siam (2008) utilize this definition in their theoretical model and embrace the previous literature on tasks. Specifically there are four sources from the task based paradigm that have been integrated in the creation of their comprehensive model; Moos and Tsu (Coping with Physical Illness, 1977), Cohen and Lazarus (Coping with the Stress of Illness, 1979), Corr (A Task-based Approach to Coping with Dying, 1992), and previous research conducted by Samson (2006). By combining aspects from the previous literature, Samson and Siam (2008) constructed a task based model that included five components; the patient's personal history and social context, cognitive evaluations of the disease, adaptation tasks, coping skills, and final outcome (see Figure 1.1).

Figure 1.1: Samson and Siam (2008)



Component 1: personal history and social context. Component one of the model refers to an individual's personal history and how it relates to their ability to adapt both positively and negatively. Specifically personal history includes ethnic origin, socio-economic status, life transition experience, and quality of social support networks (Moos & Tsu, 1977). Through the combination of these elements, Samson and Siam (2008) capture the individual variables that play a role in the process of adapting to terminal illness.

Component 2: cognitive appraisal. Component two represents the idea that individuals do not have the same response to diagnosis of a chronic illness due to the differences in perception. For this reason, two forms of cognitive appraisal are utilized within the model to address these differences; primary appraisal and secondary appraisal (Cohen & Lazarus, 1979). Primary appraisal refers to the process of conceptualizing how the illness will influence the individual's wellbeing. Secondary appraisal refers to the evaluation of coping resources to manage the demands of the illness. Samson and Siam (2008) identify this process as what allows for the completion of tasks.

Component 3: adaptive tasks. Component three is considered the core aspect of the model and the component that encompasses the specific tasks that represent aspects of human functioning (Corr, 1992). These tasks include five categories; medical, social, psychological, spiritual and vocational. Medical tasks refer to meeting the needs of the physical body and adhering to the requirements proscribed by the health professionals. Social tasks aim to gain positive social support from significant others such as family and friends. Psychological tasks refer to the maintenance of a sense of control in one's life and in regulating the emotions of the

individual. The spiritual tasks are those that contribute to the meaning given to the illness and the consequences of that illness. Finally the vocational tasks (added by Samson and Siam to Corr's task base model) refer specifically to the activity in paid and non-paid work such as occupational work or volunteer work that helps in the creation of meaning in life, social status, and establishing personal identity.

Component 4: coping skills Component four of the comprehensive task-based model consists of the coping skills utilized in the adaptation to the illness. Coping skills are seen as the specific means utilized to accomplish many of the adaptive tasks in component three. Coping skills can be both positive and negative in nature and are both mental and behavioral in nature. Examples of coping skills include denying the crisis, seeking out information, requesting emotional support, setting concrete goals or finding purpose in life (Samson & Siam, 2008). These coping tactics can be preexisting in the individual or learned during the process of adaption to the illness.

Component 5: outcome. The final component in this adaptation model is the outcome. Samson and Siam (2008) utilize two possible outcomes taken from Moos and Tsu (1977) and Cohen and Lazarus (1979). The two possible outcomes are either, a) positive or b) negative. Positive outcomes include the illness being seen as less disruptive in the person's life with a new found state of psychosocial equilibrium. Negative outcomes include a degree of psychological distress and overall decline in the individual.

Overall, Samson and Siam's Comprehensive Task-Model Approach to adaptation illustrates the process in which an individual deals with a chronic illness. This model identifies the complex nature of this process and the multitude of individual aspects that are brought into

that process. This model gives a clear understanding of the path that one must travel to reach a point of adaptation to illness.

Relational understanding of life and death. The adaptation that will be undertaken by the dying individual and those around them can be seen as the road that must be traveled and the presence of death can have an impact on that journey. For this reason it is important to have an added understanding of the relationships that can be created between life and death (Wright, 2003). The relational understanding of life and death came from a qualitative analysis of men and women in a hospice setting who were coping with death and dying. As with Samson and Siam (2008), Wright was challenged to expand the well-known stages of coping with death model (Kubler-Ross, 1969) and create a broader explanation of the experience of death and dying. Through in-depth interviews of 12 dying patients and 24 family members, Wright (2003) set out to understand the experiences of those who were terminally ill (and their families) and dealing with the inevitability of death. This undertaking led to the creation of a fluid and individualistic model to help explain how the dying and their families view life and death as a result of the prospect of death.

After the analysis of in depth interviews, Wright, (2003) concludes that there is a relational component that emerges when death is in the near future. Participants within her study described a relationship between life and death, where the two concepts were interconnected and had great influence on one another. Specifically, Wright (2003) describes six possible relationships that can emerge as a result of both living and dying concurrently. The possible relationships include, imprisoned by death, seize the day, seize the death, life and death transformed, silenced by death and waiting for death. Table 1.1, offers an explanation and example to illustrate each relationship.

Table 1.1: Possible Relationships with Death

Relationship	Explanation	Example
Imprisoned by Death	Participants in this category reported a constant thought of death. Death had an influence on every aspect of life and limited the participant's ability to look to the future, make plans or even enjoy the life they had left to live.	<i>"So the future has been taken from us. You can't dream about growing old together. We can't, I mean it's like the future has suddenly been taken from us."</i>
Seize the Day	Participants that seized the day reported a new found life meaning. As they were faced with death they began to live life more fully than before. New found appreciation for life was created.	<i>"I looked death in the eye, and now I am living...This life is a lot better than the one before."</i>
Seize the Death	Seize the death referred to participants who created a new found interest in their own death. Participants researched symptoms of their disease and how they would deteriorate. They found a curiosity in the process of death and the afterlife.	<i>"I feel like I'm getting ready to take a journey that you take once in a life time. . . . And I don't know what that's like. I don't know where it'll end. I don't know where it begins, and uh, it's rather exciting. I find it extremely exciting."</i>
Life and Death Transformed	This relationship refers to participants who found new meaning in life and in death. The definition of dying was transformed into a journey and a new form a life. Death was not the end of life but part of life.	<i>"It's not really death, but eternal reality. A doorway...It's looking beyond this life with the expectation of being with Him [Jesus] in His presence....A rejection of death."</i>
Silenced by Death	Participants in this relationship had a fear of discussing death and a strong denial that death was inevitable.	<i>"Interviewer: Both of you have very strong faith...but do you ever think about him dying? Respondent: No, he's not going to die. No."</i>

Table 1.1 (cont'd)

Waiting for Death	Participants who were waiting for death had a focus on death but not one that was imprisoning, one that was inevitable. This relationship includes the acceptance of death and that it would occur in the near future.	<i>"It was certainly intense, to a place that I hadn't ever been before-just attending death. Waiting.</i> <i>Death is the next portal, and you don't know where or when it's gonna be."</i>
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Examples taken from Wright, 2003, p. 442, 443, 445, 446, 448, 450.

The relationships that are formed are only examples of those that can develop and Wright (2003) makes it clear that these are not mutually exclusive. This explanation of coping with death does not limit the types of relationships that can occur, but makes the case that, more importantly, a relationship does occur. When death is presented in a "real" fashion, through terminal illness, this presence influences how individuals and those around them view the interconnectivity of life and death. Due to this interconnectivity, Wright (2003) argues that, "a person's dying cannot be understood without intimately understanding his or her life..." (p. 452). The experiences of one's life directly affects how they will view and cope with death and the relationship that will develop between living and dying.

The theoretical framework proposed represents the relational understanding of life and death (Wright, 2003) in combination with the process of adaptation to illness (Samson & Siam, 2008) as a way of understanding the complexities of dealing with death and dying. The added relational understanding to the task-model approach to adaptation gives a richer understanding of the depth in which mortality can impact a person's experience. The relationship between life and death influences the cognitive appraisal, adaptive tasks and coping skills utilized to come to either a positive or negative outcome. The proposed research will add to this theoretical

framework by assessing the individual stories of life and death to inform the literature and future interventions that can address the specific needs of this population.

Research Questions

This study will answer the question, “What are the lived experiences of women in late stage breast cancer, what helps them to live with this diagnosis, and what contributes to and what impedes, their optimal quality of life?” The answer to this question will inform the current research on women with Stage IV breast cancer and what needs to be included to create interventions for women with Stage IV breast cancer. To answer this question, this qualitative study will include specific research questions based on the theoretical framework presented and interview questions specific to each research question. Table 1.2 illustrates the connection between theory, research and the development of interview questions.

Table 1.2: Theory, Research and Interview Questions

Theoretical Tenets	Research Questions	Interview Questions
Personal history and social context:		
1. Event related factors	What are the lived experiences of women with stage IV breast cancer?	a. What has been your experience with cancer from diagnosis to today? b. What have been the most significant milestones throughout your cancer experience? c. Why were these significant for you?
2. Background and personal characteristics	What characteristics of the person and of their background influenced the cancer experience?	a. How have your past experiences (e.g. your childhood, values, life experiences), prior to your diagnosis, influenced your cancer experience?

Table 1.2 (cont'd)

3. Physical and socio-cultural environment	What are the environmental factors that influence the experience?	a. Tell me about the things in your [environment, culture, community, family], that affected your cancer experience.
Cognitive appraisals:		
4. Primary cognitive appraisal (event seen as a threat)	How do woman react to their diagnosis and how do they make sense of having a terminal illness?	a. How did you react to your diagnosis? b. Have you come to terms with your diagnosis? c. If yes, how? If no, describe what you are struggling with?
5. Secondary cognitive appraisal (event seen as a challenge)	How do women receiving a terminal diagnosis face up to the challenge of cancer?	a. When you received your diagnosis, what did you wish you knew then that has helped you along the way to overcome the challenge of cancer?
Adaptive Tasks:		
6. Physical	What physical demands are placed on the body and how are they met?	a. How did you adapt to the physical symptoms of the disease and the effects from treatments?
7. Psychological	What impedes healthy psychology and how do women create emotional balance, a positive self image, and autonomy?	a. Describe your emotional reactions to the diagnosis? b. What have your psychological responses been to the diagnosis? c. How have you overcome these?
8. Social	What social supports are needed in the experience of cancer and how are they established?	a. How have family, friends and community supports contributed to your experience with your illness?

Table 1.2 (cont'd)

9. Spiritual	How is spirituality affected through the cancer experience and how is it cultivated?	a. What role has spirituality played in living with cancer?
10. Vocational	What influence does the cancer have on work and recreation?	a. How has your work and recreational life been effected by your cancer? b. How have you responded to this?
Coping Skills	What coping skills are utilized throughout the experience of cancer?	a. What have you done individually to cope with your disease? b. What psychosocial interventions have you participated in? (e.g. therapy, groups, family therapy, consultation with religious figure) c. Did these help and why or why not?
Outcome: 11. Quality of life	What contributes to, and impedes optimal quality of life?	a. Describe your quality of life. b. How would you rate your life quality on a scale from 1-10? c. What would need to be present in your life to make it better?
12. Psycho-social equilibrium	b. How is balance created in everyday life?	a. How do you create balance in your life, personally, socially, spiritually, etc.?
Relationship between life and death	How does this population view life and death subsequent to their diagnosis and throughout their cancer experience?	What are your thoughts and feelings regarding life and death? a. Has the meaning of life changed for you? b. Have your thoughts on death changed?

Relevance of the Study

The current study is relevant for several reasons. First, the literature on interventions for women with Stage IV breast cancer is limited. Specifically there is a lack of psychosocial research that has been conducted on this population, but more importantly there is a severe lack in diversity of the research that exists. Much of the research on interventions for women with a diagnosis of Stage IV breast cancer (Spiegel, et al., 1981; Spiegel, et al., 1983, Spiegel, et al., 1989; Classen, et al., 2001; Goodwin, et al., 2001; Geise-Davis, et al., 2002; Spiegel, et al., 2007; Butler, et al., 2009) is monopolized by many of the same researchers and utilize the same supportive-expressive group foundation. This study will be utilized to inform the formation of alternative interventions for women with metastatic/stage IV breast cancer. The qualitative data will illustrate some of the specific needs that this population is lacking and what information and methodologies are the most beneficial to increasing the quality of life for this population.

Secondly, the qualitative analysis will change the focus of much of the research on group interventions from a focus on increasing the survival time of women with metastatic breast cancer, to finding ways to increase quality of life in the time that they have left to live. Increasing survival time is a common outcome measure used to assess intervention efficacy. Shifting the focus from trying to increase survival and length of life to creating quality life, regardless of time left to live, is a more beneficial and attainable goal. The ways in which quality of life will be addressed will come directly from the information gathered from women representative of the Stage IV breast cancer population.

Finally, this study will give voice to a population of women who are absent from much of the psychosocial literature for women with breast cancer. By utilizing qualitative methodologies this study will gain a greater depth of understanding into the experiences of having and living

with a stage IV diagnosis. Additionally, this study will expand the limits of self-report assessments which are represented in much of the literature, to help in the creation of beneficial and efficacious interventions for this population of women. The breadth of the breast cancer literature is lacking in qualitative analysis for this population of women, how they experience their severe cancer, what needs they have physically, psychologically, socially and spiritually and how death and mortality influence their lives. For women with metastatic breast cancer relationships between life and death are extremely relevant and through this study that relevance will be captured.

CHAPTER 2: LITERATURE REVIEW

Breast cancer is a frequently occurring disease. In 2010 approximately 261,100 women were diagnosed (American Cancer Society, 2010) with 1 in 8 women receiving a diagnosis of breast cancer at some point in their lives (Ries, 2005). These numbers represent a significant proportion of women who face the many difficulties that are prevalent in the face of a breast cancer diagnosis. Among this population there is great variation in the severity, symptoms, and prognosis. Due to the multitude of factors that influence the severity of this disease, the American Joint Committee on Cancer has provided a staging system to help understand and classify the differences in breast cancer severity (see Appendix A).

There are eight distinctive breast cancer stages (i.e. 0, I, IIA, IIB, IIIA, IIIB, IIIC, IV). The stage diagnosis system has three categories of variation that are utilized in understanding the typology of the breast cancer. These categories include information on the primary tumor, information specific to the regional lymph nodes surrounding the tumor, and absence or presence of a distant metastasis. A distant metastasis is the presence of cancer cells that are not localized to the primary tumor or regional lymph nodes, but which have spread to other areas within the body (Singletary, et al., 2003). The information specific to tumor refers to the size of the tumor (from 0.1cm to > 5cm) and the placement of the tumor (i.e. in the breast, attached to the chest wall or attached to the skin). The regional lymph node status is determined by the presence or absence of cancerous cells in lymph nodes that are regional to the breast and the type of lymph nodes that are affected (i.e. axillary, ipsilateral axillary, internal mammary, ipsilateral internal mammary, infraclavicular, supraclavicular). All stages of breast cancer, regardless of severity have some physical and psychological effects on the women that receive the diagnosis, both from the diagnosis itself and from the treatments that follow. Stage IV breast cancer, however, is

defined as the most severe form of breast cancer with the woman having cancer appear in both a primary tumor, regional lymph nodes and the cancer appears in another area of the body (distant metastasis).

Medical Treatments and Physical Symptoms

The literature regarding the differing types of medical treatments for women with diagnosed breast cancer is abundant. New and experimental treatments are emerging all the time; however, there are several treatments that are commonly utilized with some if not all stages of breast cancer. Table 2.1 describes a sample of some of the standard treatments for breast cancer along with commonly experienced physical side effects

Table 2.1: Common medical treatments and side effects.

Type of Treatment	Basic Description	Common Side Effects of Treatment
Surgery	<p>Mastectomy: Removal of all breast tissue. Common utilization of this surgery occurs when a tumor is larger than 5cm or if the breast is small and lumpectomy would leave too little breast tissue.</p> <p>Lumpectomy: Removal of the tumor and a small amount of tissue surrounding the tumor. This procedure can be as effective as Mastectomy when the cancer is central to one site in the breast, the tumor is under 4cm and there are no cancer cells in tissue surrounding the tumor.</p> <p>Lymph node removal: The removal of infected lymph nodes. This surgery is utilized in combination with Mastectomy or Lumpectomy to determine the extent of the cancer as cancer in the lymph nodes is associated with an increased risk of cancer cells in other parts of the body.</p>	<p>Lumpectomy: Pain in healing, possible distortion of the breast, need for radiation therapy, possible drain, possible infection.</p> <p>Mastectomy: Removal of breast, pain in healing, possible drain, possible infection, need for prosthesis or reconstruction, stiffness in arm.</p> <p>Lymph node removal: Risk of lymphedema (swelling of soft tissue in the arm, hand, breast, trunk or abdomen due to fluid build up), pain in healing,</p>
Chemotherapy	The injection of one or more medicines that prevent cancer cells from growing and spreading by destroying the cells and stopping them from dividing.	<p>Anemia</p> <p>Diarrhea</p>

Table 2.1 (cont'd)

		<p>Fatigue</p> <p>Fertility issues</p> <p>Hair changes</p> <p>Infection</p> <p>Memory loss</p> <p>Mouth/throat sores</p> <p>Nausea</p> <p>Vomiting</p> <p>Weight changes</p>
Radiation Therapy	The use of a specialized high energy beams that damage the cell DNA to stop cell division.	<p>Red and irritated skin</p> <p>Armpit discomfort</p> <p>Chest pain</p> <p>Fatigue</p> <p>Heart problems</p> <p>Lowered white blood cell count</p> <p>Lung problems</p>
Hormone Therapy	Medicines taken to lower the amount of hormone estrogen in the body and to block the action of estrogen on breast cancer cells.	<p>Bone and joint pain</p> <p>Nausea</p> <p>Vomiting</p> <p>Fatigue</p> <p>Hot flashes</p> <p>Headache</p> <p>Blood clots</p> <p>Mood swings</p>

(Retrieved from www.breastcancer.org, October, 11 2011)

The decisions on what types of treatments are used depend on the stage of breast cancer, the health of the person, and prognosis. These decisions need to be carefully considered and

made in collaboration with the individual with breast cancer, the oncologist, physicians, and others caring for the individual.

Breast Cancer: Physical Disease but Mentally Draining

Cancer is a disease of the cells, where invasion and destruction of tissue create life threatening conditions; in addition, treatment for this cancer can have physical effects such as pain, nausea, and the like. Mentally, however, this disease can be just as ruinous as it is physically. There is strong evidence to suggest that a diagnosis of breast cancer brings a substantial increase in negative emotions and psychological distress, specifically anxiety and depression (Compas & Luecken, 2002; Epping-Jordan, et al., 1999; Millar, Purushotham, McLatchie, George, & Murray, 2005). This distress does not simply begin and end with the cancer, but can also be persistent months and even years after the diagnosis, due to fear of the cancer re-emerging, the continued need for doctors' appointments, and the strain that this disease can put on the individual and those around them.

Literature presents strong evidence that psychological symptoms are common among women with breast cancer. Through the use of interviews, focus groups, and batteries of assessments, women have been examined in order to understand the psychological distress that is experienced (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Spencer, et al., 1999). Concerns among women range broadly, but there seems to be consensus that realities of breast cancer diagnosis and treatment exist such that pain, threat of death, harm from treatments, healthcare bills, uncertainty, and sexuality/sexual functioning, play a role in breast cancer diagnosis, treatment, and survival (Ferrell, et al., 1997; Spencer, et al., 1999; Yurek, Farrar, & Andersen, 2000). These types of concerns can lead to difficulties in psychological distress such as anxiety,

depression, and difficulties in adjustment. In one study, a sample of 400 women was assessed in the first year after receiving a diagnosis of breast cancer. It was found that one quarter of the women maintained clinically significant levels of psychological morbidity as assessed by the General Health Questionnaire throughout the one year period (Millar, et al., 2005). This study illustrates the severity of the psychological symptoms that can occur in women with breast cancer. Breast cancer has a clear influence on the psychology of those who suffer with it.

Range of Adaptation

The diagnosis, treatment, and survival of breast cancer are experienced differently by each woman. Although research has shown that all endure a certain level of negative psychology, there are differences that have been found among the breast cancer population. A multitude of variables can influence the psychological adjustment to cancer including personal variations such as level of optimism (Epping-Jordan, et al., 1999; Jones, Cheng, Jackman, Rodin, Walton, & Catton, 2010), social support (Carver, Smith, Antoni, Petronis, Weiss & Derhagopian, 2005; Compas & Luecken, 2002; Lindop & Cannon, 2001), age (Epping-Jordan, et al., 1999; Jones, Cheng, Jackman, Rodin, Walton, & Catton, 2010; Lindop & Cannon, 2001), stage of diagnosis, and the types of treatments that are utilized (Lindop & Cannon, 2001; Yurek, et al., 2000). Psychological distress, as defined by anxiety, depression, and other difficulties adjusting to the disease, also varies within the process of diagnosis and treatment, with the highest psychological distress reported near time of diagnosis and a drop in distress subsequent to surgery (Carver, et al., 1993). Although distress may be reduced for some post treatment, evidence shows that others experience symptoms of distress throughout the process, at diagnosis, during treatment, and post treatment (Jim, Andrykowski, Munster, & Jacobsen, 2007). Specifically the period post

treatment has been shown to be distressing as this is a “waiting period” where patients are waiting to see the outcome of the treatment (Arnold, 1999).

As with many chronic illnesses, adaptation is dependent on the individual case, the support that they receive, the severity of the disease, and the ability to cope. Although specific dispositional factors influence levels of distress and intrusive thoughts, the coping mechanisms that are utilized are important predictors in levels of anxiety and depression (Epping-Jordan, et al., 1999). One study using a sample of 80 women, suggests that across all stages of the disease, the utilization of coping strategies such as problem solving and cognitive restructuring were associated with less distress both at three and six months post diagnosis. Coping strategies of self-criticism and social withdrawing behaviors predicted more emotional distress over the 6 month period (Epping-Jordan, et al., 1999). There are a large range of changes that women with breast cancer experience, and the ways in which they react and choose to handle the symptoms of the disease greatly predicts the amount of anxiety and depression that is felt.

An additional variable that is of importance is the stage of breast cancer. The stage of cancer is related to the amount of psychological distress experienced. Evidence shows that the variable of cancer stage is an important predictor of distress 6 months after diagnosis (Compas, et al., 1999). Additionally, women experience symptoms of psychological distress due to a poorer prognosis associated with stage severity. In other words, women who have a higher stage diagnosis experience more psychological distress.

Psychological Impact of Stage IV Breast Cancer

The nature and prognosis of stage IV breast cancer creates a unique situation when compared to other stage categorizations. Although, women with breast cancer, regardless of

stage, experience both physical and psychological distress, women with a stage IV diagnosis have a poorer prognosis, and must endure multiple medical treatments that can include combinations of surgery, chemotherapy, radiation therapy, and hormone therapy (Hortobagyi, 2002). This systemic treatment can lead to many painful and difficult physical symptoms and side effects (see Table 2.1). In addition, the difficulties of dealing with a poor prognosis and the effect that a diagnosis can have on the woman, as well as family and friends, creates a unique experience of distress. "...Facing the prospect of a foreshortened future, in addition to the steady decline of health, ongoing medical treatment, and the effect of the medical condition on loved ones, is certain to bring forth an array of painful and difficult emotions [for women with stage IV breast cancer]" (Classen, et al., 1996, p. 434). While this has been cited in the literature, there is limited research that focuses directly on the psychological effects of metastatic or stage IV breast cancer specifically; however, the diagnosis of stage IV is frequently seen to be more distressing than stages 0-IIIc due to the severity of the disease at this stage (Warren, 2010). Evidence shows that the psychological impact and physical symptoms of this disease, matched with facing mortality is a unique experience for women with a stage IV diagnosis.

Theory and Literature

This form of breast cancer is a multifaceted experience influenced by a multitude of factors, many of which are not thoroughly researched (Warren, 2010). The limited examination of factors including personal history, social context, cognitive appraisal, adaptive skills, coping skills, relationships with life and death, quality of life and relational distress can be seen within the literature. These factors, in association with the theoretical framework of the current study, give an overview of the literature specific to metastatic breast cancer and the psychological impact that this disease can have on this population.

Personal history. Personal history refers to the individual aspects of a person's background and the experiences that they have had in their lives. These characteristics play a role in how an individual adapts to illness (Samson & Siam, 2008). The literature on women with metastatic breast cancer does not give a thorough illustration of the multitude of personal variations that exist in women in this population. Although limited, research does allude to the importance of examining personal history. Butler, Koopman, Classen and Spiegel (1999) assessed how traumatic stress and past life events influence stress in women with metastatic breast cancer. In a population of 125 women, severe intrusion and avoidance symptoms were assessed in relation to the experience of having cancer. These symptoms were found to be related to the circumstances of the individual's current and past life experiences. Specifically, women with metastatic breast cancer were found to be at elevated risk for these symptoms if they had experienced a stressful life history (Butler, et al., 1999). The current life stress experienced in regards to metastatic breast cancer coupled with past and current traumatic events were found to overwhelm the women's ability to cope with their disease in a healthy way. This study shows evidence that a person's history of stress and trauma influences that person's capability to cope.

An additional study examined five women with metastatic breast cancer utilizing an in depth phenomenological approach (Chunlestsukul, et al., 2008a; 2008b). This research specifically examined the women's ability and capability to prepare for their death in the face of a metastatic breast cancer diagnosis. Factors that enabled and inhibited the death preparation were examined and the individual's personal history was found to be an influential factor. Having experienced difficult deaths in the past lead to feelings of guilt and worry regarding how the woman's personal death would affect those around her. Additionally, the individual's personal and cultural attitudes towards death were also a factor in how the women viewed the

preparation process of their own death (Chunlestsukul, et al., 2008b). These personal history factors influenced the emotions that were experienced around the thought of death (i.e. more guilt and worry if difficult death had been experienced) and the actions taken in death preparation (e.g. talking about death with family, creating a living will).

The list of personal history factors is not limited to experiences of death and trauma/stressful events. However, the research on how personal history factors influence the adaptation, coping, and experience of metastatic breast cancer is greatly underdeveloped. Further personal history characteristics need to be examined to form a more thorough picture of women with metastatic breast cancer.

Social context. The social context, according to Samson and Siam (2008), is linked to personal history. However, social context has been examined, specifically, in the literature in regards to how a women's social context influences her experience of stage IV breast cancer. Three studies have specifically examined the factor of social context. Turner-Cobb, Sephton, Koopman, Blake-Mortimer, and Spiegel (2000) utilized cortisol levels to indicate how an individual's social context influences stress levels that are experienced with a diagnosis of metastatic breast cancer. One hundred and twenty-five women with documented metastatic breast cancer were examined. It was found that the greater quality of social support that the women received from friends, family and community, the lower their cortisol concentrations. This was indicative of healthier neuroendocrine functioning and less stress in the individual. Additionally, those who were able to share pleasurable activities with others and who had more tangible support also experienced lower levels of cortisol (Turner-Cobb, et al., 2000). These researchers concluded that social support acts as a buffer for psychosocial stress and enables the individual to perceive stressful events as less stressful.

Two additional studies found specific links between the social context of an individual with metastatic breast cancer and how they experience their cancer. Butler, et al. (1999) found that women with larger social networks reported fewer symptoms of avoidance and were better able to handle their diagnosis. Additionally, having a larger network of close friends and family available to interact on a daily basis led to less opportunity for isolation and greater opportunity to think about and discuss their illness (Butler, et al., 1999).

The inclusion of a social network that includes women going through a similar disease experience was also found to be necessary in the preparation for death (Chunlestskul, et al., 2008b). Specifically it was found that women whose social context included other women with metastatic breast cancer were able to experience feelings of validation and normalization as they experienced challenges to mortality. Preparing for death along with the difficult emotions associated with this, such as depression and anxiety, were normalized by their social networks (Chunlestskul, et al., 2008b) as other women were experiencing similar feelings. This validation and normalization led to a greater ability to cope as these women prepared to die.

The social context that women with metastatic breast cancer utilize has important implications for how they experience their diagnosis, acceptance of their cancer, and preparation for their death. Additional influences of social context need to be examined that reach beyond these factors and create greater understanding of the types of social relationships that are most beneficial in an attempt to help this population live in a healthy way and with a high quality of life.

Cognitive appraisal. Samson and Siam (2008) utilize the tenet of cognitive appraisal as a way to explain how those with chronic illness react to and find meaning in their situations. The

literature specific to women with metastatic breast cancer examines cognitive appraisal with a focus on primary cognitive appraisal; conceptualizing how the illness will influence the individuals' wellbeing (Cohen & Lazarus, 1979) and seeing the event as a threat (Samson & Siam, 2008). In an examination of the psychological reactions to the prognosis of metastatic breast cancer, women responded with feelings of disappointment, sadness, anxiety, and worry about the future (Svensson, Brandber, Einbeigi, Hatschek, & Ahlberg, 2009). Additionally, women with stage IV breast cancer have reported feeling bad-tempered, down, depressed, and less tolerant than they had prior to their diagnosis (Luoma & Hakamies-Blomqvist, 2004).

Outside of emotional reaction, higher order philosophy has also been assessed. A sample of one hundred women with a stage II (52) and stage IV (48) diagnosis were examined to compare adjustment to the disease. It was found that women with a stage IV diagnosis held a higher level of fatalism, the philosophy that future events are unchangeable and determined by fate, which led to higher levels of anxiety and depression than those with a stage II diagnosis (Schnoll, Harlow, Brandt & Stolback, 1998). Women with stage IV breast cancer more often conceptualized their disease in terms of fatalism due to the incurability of metastatic cancer. This range of emotional reactions to the disease is representative of primary cognitive appraisal and shows how women react to having this disease and how they conceptualize their prognosis.

Unfortunately, literature specific to this population is limited in the examination of secondary cognitive appraisal; the evaluation of resources, management of the illness (Cohen & Lazarus, 1979), and seeing the illness as a challenge (Samson & Siam, 2008). The literature has rarely moved beyond the initial reactions to the diagnosis of metastatic breast cancer. One study, however, examined the characteristic of gratitude and the role of gratitude in women with metastatic breast cancer (Algoe & Stanton, 2011). Gratitude can be seen as a secondary cognitive

appraisal as it is used as a resource to manage the illness and a way to combat distress associated with the illness. In this study (Algoe & Stanton, 2011), a sample of 54 women with metastatic breast cancer were assessed to examine their adaptive functions and emotional responses to benefits encountered by this population. The social function of gratitude was a specific focus for the research. It was found that women felt gratitude when they were able to conceptualize their disease in a way that left them open to expressing their emotions and accepting support from others (Algoe & Stanton, 2011).

Additionally, Schnoll, et al., (1998) found differences in secondary cognitive appraisal between women with a stage II and stage IV diagnosis. For women with stage IV breast cancer, conceptualizing the illness as hopeless was associated with greater levels of anxiety and depression and lower quality of life. Additionally, positive attitude and positive reappraisal of the situation were associated with lower levels of anxiety and depression and higher quality of life (Schnoll, et al., 1998). The conceptualization and cognitive appraisal of the experience of metastatic breast cancer has been shown to greatly influence how an individual experiences the disease and her levels of psychological distress.

Adaptive skills. Adaptive skills are the specific tasks that make up human functioning and are needed to create healthy adaptation to a chronic illness (Samson & Siam, 2008). In accordance with the theoretical framework, these tasks are medical, social, psychological, spiritual and vocational. Although there are a multitude of tasks that can be accomplished to lead to healthy adaptation to metastatic breast cancer, the literature specific to this population has only touched on a limited selection of specific tasks. Specifically, social, psychological and vocational tasks have been the focus in the literature.

Algoe and Stanton, (2011) show strong evidence in the need of social adaptive skills and the benefits that comes from completing social tasks. Welcoming interpersonal support and seeing benefit in social interaction leads to greater levels of gratitude and positive emotions. Conversely, when responsiveness to social support is low the supportive attempt can backfire and lead to negative emotions from both the patient and the person providing the support (Algoe & Stanton, 2011).

An additional example of social tasks can be seen in the process of preparing for death. Seeking social support through individual counseling, group support, and talking with friends, family and professionals has been found to help create greater success in adaptation to metastatic breast cancer (Chunlestsukul, et al., 2008a). More specifically, evidence shows that women with metastatic breast cancer utilize a number of social tasks to adapt to their disease including utilizing their faith community, spending time with pets, and airing concerns and thoughts with friends and family (Svensson, et al., 2009).

Psychologically there are many tasks that can be completed to help in the process of adaptation including regulating emotions, creating a sense of control wherever possible, and creating a positive self-image (Samson & Siam, 2008). Literature specific to this population suggests tasks such as analyzing thoughts, utilizing positive and mindfulness thinking (Svensson, et al., 2009), expressing emotions (Classen, et al., 1996), and gaining knowledge and education regarding treatments and the disease progression (Chunlestsukul, et al., 2008a), can help to create positivity and acceptance in the experience of metastatic breast cancer.

Vocational tasks utilized as adaptive skills have been less addressed specific to women with stage IV breast cancer. Svensson, et al., (2009) was the only study to include the benefit of

women continuing to go to work as a way to create stability in their lives. Samson and Siam (2008) see vocational tasks as a way to help create meaning within the chronic illness and suggest tasks such as working a job and volunteering as a way to adapt to the situation. Literature specific to metastatic breast cancer needs to further evaluate the vocational tasks that are utilized.

Additionally, specific spiritual tasks such as creating hope and meaning in the face of the disease are underdeveloped and in need of further inquiry. Evidence shows that for women with breast cancer in general, having a strong sense of meaning and peace with life at baseline assessment and having an increase in meaning/peace over a 6 month period predicted a decrease in depressive symptoms and an increase in vitality for a population of 418 women (Yanez, et al., 2009). Additionally, an increase in meaning and peace in one's life was related to improved mental health and lower cancer related stress with having a sense of faith predictive of having successful adjustment to breast cancer (Yanez, et al., 2009). Acceptance of a breast cancer diagnosis is also associated with the development of a belief system that creates meaning in the cancer experience (Blow, et al., 2011). The adaptive tasks of spirituality are important within an overall breast cancer population and need to be assessed specifically for women with a stage IV diagnosis.

Coping skills. The coping skills that women with metastatic breast cancer utilize to adapt to their disease is an additional area that has been examined in the research. Coping skills are seen as the means in which adaptive skills are accomplished and can be both positive and negative in nature (Samson & Siam, 2008). As with all information regarding this population, the research specific to coping skills is limited. However, there is evidence that the process of coping with the disease mediates the psychological distress (as defined by anxiety and depression) and quality of life of the women. Disease stage (i.e. stage II vs. stage IV) was not a direct predictor,

but influenced distress and quality of life through the mediation of coping styles (Schnoll, et al., 1998).

Research has shown several differing coping skills that women with stage IV breast cancer have utilized. Women with a stage IV diagnosis reported utilizing emotional expression and a fighting spirit as a strategy of coping. It was found that these coping skills were associated with reduced levels of anxiety, depression, hostility, confusion and fatigue in a sample of 101 women (Classen, et al., 1996). Additionally specific coping skills utilized in the reduction of pain were assessed in a population of 80 women with metastatic breast cancer. The most common coping strategies were withdrawal and inactivity, specifically relaxation, taking pain medication and trying to accept their pain, (Arathuzik, 1991). Attempts to problem solve and reduce anxiety and depression associated with the pain were also commonly observed as coping skills. The individual coping, beyond dealing with symptoms of pain and the use of fighting spirit and emotional expression have not been observed in the research.

The research on coping skills utilized in a stage IV population does include the coping strategies associated with couple relationships (Badr, Kashy, Carmack, Cristofanilli, & Revenson, 2010). “Couples facing stage IV breast cancer must cope with the stressors that can affect both partners’ quality of life as well as the quality of life of their relationship,” (Badr, et al., 2010, p. 169). A sample of 191 women with stage IV breast cancer and their partners were examined on measures of distress, relational satisfaction, and coping styles. Results showed that distress was experienced by both partners with differences in positive and negative coping. Common positive dyadic coping included joint problem solving, coordinating everyday demands, relaxing together, mutual calming, sharing, and expressions of solidarity. Common negative dyadic coping involved mutual avoidance of the problem and withdrawal. Evidence

from this study shows that women and their partners who utilize negative coping experience significantly greater levels of distress at all times with higher distress felt by the woman. In contrast, the utilization of positive coping was found to be mutually beneficial in lowering distress of the participants and in creating greater couple satisfaction for both parties (Badr, et al., 2010).

Coping skills are of great importance to a population who faces mortality and must cope with the many symptoms, both physical and psychological that are associated with the disease of metastatic breast cancer. The narrow understanding of coping strategies of this population does not illustrate a clear picture of the types of coping skills that this population utilizes. Additionally, there are barriers to coping.

Life and death. Wright (2003) explores the relationship that is created between life and death in the face of a chronic illness. Several examples of relationships that can be created in the face of inevitable death are given and the importance of explore this relationship has been shown. Specific to the population of women with stage IV breast cancer the examinations of the processes that occur as death becomes more apparent are needed. Butler, et al., (2003) examined a sample of 59 women with metastatic breast cancer and assessed their levels of psychological distress and pain at three points in time (T1, T2 and T3), each closer to the death of the patient. The means on all measures of psychological distress were stable from T1 to T2, but from T2 to T3 showed significant increases in psychological distress (Butler, et al., 2003). Researchers noted that it was not the self-reported pain nor the passing of time that accounted for these significant increases, but rather, the closer one came to death the greater the psychological distress that was experienced.

To date, there has been only one set of studies that have examined the complex relationship that women with stage IV breast cancer have with death. Chunlestsukul, et al., (2008a; 2008b) examined the lived experiences of women with metastatic breast cancer in regards to their preparations for death. In these two studies (Part I: Preparations and Consequences and Part II: Enabling and Inhibiting Factors) 5 women were interviewed twice about their experiences. Several findings from these studies speak directly to the relationship between life and death that can be created. Generally, women prepared for death by acknowledging their grief, preparing mentally, seeking information and support, preparing family, and preparing for the end of life to come. Specifically, role delegating, letting go, creating life projects (e.g. creating scrapbooks of memories, sharing life stories with family), and living full and joyous lives within the time left, led to important outcomes including better preparation for death, family and self-growth, peaceful feelings, and the learning of life lessons (Chunlestsukul, et al., 2008a). The main barrier to the above mentioned experience was the negative social stigma associated with death which made preparation difficult. Attitudes, fears and discomfort with the topic of death created some difficulties in holding discussions and moving death from a negative to a positive light (Chunlestsukul, et al., 2008b). Further research is necessary to expand the literature specific to the relationship with death and to fully understand the process that this population must endure.

Quality of life. Quality of life is one variable, in addition to the tenets of Samson and Siam (2008) and Wright (2003) that differs between stages of breast cancer, and which grows worse as the disease progresses, and is an important facet in the lives of women with metastatic breast cancer. “Metastatic breast cancer is incurable...therefore, the goals of the treatment must be palliation of symptoms and prolongation of life without compromising an acceptable quality

of life,” (Costantino, 2002, p. C17). This goal is difficult to achieve due to the multiple distresses that these women endure. One study using a sample of 361 women of all stages showed that women with metastatic breast cancer experience significantly lower scores on health related quality of life. Additionally, increases in pain due to treatments and the distant metastasis along with decreases in mobility which is more common for this population, lead to a lowered quality of life (Lidgren, et al., 2007). The progression to metastasis has a greater threat to life which increases emotional trauma and decreases quality of life (Siddiqi, et al., 2009).

The literature on quality of life and women with a stage IV diagnosis has focused on quality of life factors specific to the treatments that this population encounters. In one study using a sample of 210 women with metastatic breast cancer (Karamouzis, Ioannidis, & Rigatos, 2007), decreases in quality of life factors (including body image, sexual functioning, future perspective, systemic therapy side effects, breast symptoms, arm symptoms and upset by hair loss) were found to be common in those undergoing chemotherapy and more common in those undergoing palliative care (i.e. treatment other than chemotherapy). Additionally, women who were not undergoing chemotherapy (many of which were receiving radiation therapy) experienced lowered levels of physical functioning, role functioning, and emotional functioning (Karamouzis, et al., 2007). Chemotherapy and hormone therapy, for example, has been shown to lead to experiences of induction in menopause, hot flashes, fatigue, and weight gain which cause not only physical, but emotional and sexual problems, which creates a decrease in health related quality of life (Weinfurt, et al., 2004). Unfortunately, the research on the topic of quality of life and women with metastatic breast cancer is limited and there is a great need for prospective studies that can accurately estimate the quality of life for this population (Karamouzis, et al., 2007).

Relational distress. Living with cancer can also create relational distress. Specifically, the literature is limited to examinations of couple relationship with only one additional study examining the adaptation of this disease and the effects it can have on partners. This study examined a sample of 125 women with stage IV breast cancer and a sub-sample of 48 of these women and their partners. The study set out to understand the mood disturbance of these women in relation to their partner status, quality of their relationship, and their partners' coping and mood disturbance (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegle, 2000). Relationships between distress such as anxiety, depression, fatigue, anger, confusion and vigor, and the couple were found, with more distress reported when couple satisfaction was low, and higher individual distress for the women with cancer when the partner reported higher levels of mood disturbance. The interconnection between distress and couple cohesion is evident in this study. Through the lens of family systems, these findings are not unexpected with the commonly held belief that one person in the family affects the entire family system (Becvar & Becvar, 2006). Therefore, the distress and difficulties associated with a stage IV diagnosis are sure to affect each relationship within the family.

The research specific to this population is clearly limited and in need of additional, in-depth examinations of the specific nature of a stage IV diagnosis. Overwhelmingly, the literature, although limited specific to this population, supports the notion that women with metastatic breast cancer have uniquely difficult experiences when compared to those with other stages of breast cancer. The incurability, multiple treatments, and physical and psychological symptoms endured, leave this population in need of interventions to address these concerns. Specifically, increasing the quality of life for this population is immensely important in improving the life that these women have left.

Stage IV Specific Psychological Interventions

Women with metastatic breast cancer have commonly not been included in much of the literature on breast cancer interventions. The long term course of this stage of cancer and the increase in difficulty to cure a cancer that has spread, places this population in great need.

Women with Stage IV metastatic breast cancer are a population that has been under-researched in the breadth of intervention literature. Specifically there is a lack in diversity among psychological interventions, with group intervention being the only approach represented in the literature. Although there are limited studies that have focused on this specific population, a total of twelve articles have examined group interventions with a population exclusive to a metastatic or stage IV diagnosis. These group interventions utilize two main frameworks; supportive expressive, and cognitive behavioral.

The research specific to the population of metastatic breast cancer began in the 1980s. Spiegel, Bloom, and Yalom, (1981) conducted a support group for 86 women with documented metastatic carcinoma of the breast. The sample was randomly selected to attend either the treatment (support) group or a control group. Due to attrition (e.g. illness, weakness) 34 women were placed into the support group and 54 were placed into the control group. The supportive group intervention consisted of weekly, 1.5 hour meetings with groups composed of 7-10 participants. Groups were conducted over a one year period. Each group had two leaders, a psychiatrist, social worker and/or a counselor who was a survivor of breast cancer. Groups were semi-unstructured and collaborative in nature, although specific content was addressed in each session. Discussions included death and dying, familial problems, treatment concerns and difficulties, communication with physicians and living life fully in the face of a terminal illness.

Researchers assessed participants with a battery of questionnaires, pre intervention and at 4 month intervals, including health locus of control, Profile of Mood States (POMS), self-esteem, maladaptive coping responses, phobias, and level of denial.

Results indicated significant differences in overall mood disturbance, tension anxiety, fatigue, vigor and confusion when compared to the control (Spiegel, et al., 1981). Group members also reported a decrease in fearfulness and maladaptive coping responses. Additionally it was noted the participants reported that the group experience decreased their feelings of isolation and helped in “detoxifying” dying both with the discussions of death and having experienced the severe illness and loss of other members within the group. This supportive group intervention showed evidence of success in reducing psychological distress and increasing relational closeness between participants. Discussing topics of death and dying in the face of terminal illness seemed to be beneficial specifically with the attrition of members within the group during the intervention process (Spiegel, et al., 1981).

Spiegel, and Bloom, (1983) continued research in the area of understanding the efficacy of the same support group with a sample of 54 women with metastatic breast cancer. In this study the supportive group intervention was utilized with 90min sessions, once per week. Participants were randomly assigned to one of three groups; supportive group therapy, supportive group therapy with a 5-10 minute self-hypnosis training at the end of each session with instructions for home hypnosis, or a control group. The added hypnosis was directly utilized to help in the reduction of pain. Specifically, participants were instructed to not fight against their pain but to filter their pain by utilizing imagery of different sensations in the areas of the body where pain was felt, such as an icy cold feeling or a warm tingly feeling (Spiegel & Bloom, 1983).

The purpose of this group comparison was to assess how the group intervention and intervention matched with hypnosis, influenced levels of pain and stress experienced by the participants. The sample was assessed pre intervention and at a 4 month period over the course of one year of treatment; measures included the POMS and Pain Rating Scale. Results indicated that participants in both treatments groups (with and without hypnosis training) reported significantly less pain and suffering throughout the year of treatment when compared to the control. Group members in the treatment groups did not report shorter, nor fewer incidents of pain, however were better able to respond to the pain when it occurred (Spiegel & Bloom, 1983). Researchers also attribute this decrease in pain and suffering with the previously found decrease in anxiety and mood disturbance (Spiegel, et al., 1981).

Spiegel, Helena, Kraemer, Bloom and Gottheil, (1989) utilized a ten year follow up of the sample of participants from the Spiegel and Bloom, (1983) study to assess divergence in survival time of the women comparing the two treatment groups and the control. At the ten year follow up only three of the participants were currently alive and death records of the remaining participants were collected. It was found that women in the treatment groups survived an average of 36.6 (SD 37.6) months post intervention compared to those in the control surviving only 18.9 months (SD 10.8). This finding was a significant different. Researchers made the conclusion that their treatment intervention (both with and without hypnosis) increased survival time within women with metastatic breast cancer (Spiegel, et al., 1981). Although this is a significant finding, it is questionable with regards to the large standard deviations among participant means and with the multitude of variables that are associated with each woman in the group. Differing types of treatment, social support, optimism, coping skills and physical differences between

participants were not controlled. For this reason it is difficult to conclude that the intervention was the “cause” of an increase in survival for these women.

Research in the area of efficacy of psychological support groups for women with Stage IV breast cancer continued with an additional study focused on increasing survival time.

Cunningham, Edmonds, Jenkins, Pollack, Lockwood, and Warr, (1998) assessed 66 women randomly assigned to either a supportive and cognitive behavioral group or a control group consisting of cognitive behavioral at home study material. The treatment group was conducted over the course of 35 weeks with 2 hour weekly meetings. Researchers conducted several pilot studies utilizing the Spiegel, et al., (1981) support group with added cognitive behavioral components before conducting the current investigation. The final group was the supportive group previously established with 20 cognitive behavioral homework assignments given to participants. The outcome measure for this sample was time of survival subsequent to entry into the study. Results showed that the support group plus cognitive behavioral homework demonstrated no significant difference in survival time when compared to the control. Although care was taken in matching the comparison groups in severity of illness, weakness in the study was found with alternative treatments being utilized by both the treatment and control group (Cunningham, et al., 1998). Overall it is difficult to create a direct link between increase in survival and support group intervention.

An additional intervention utilizing cognitive behavioral techniques is seen in an efficacy study conducted by Edelman, Bell and Kidman (1999a). One hundred and twenty-four women with metastatic breast cancer were recruited and randomly assigned to either a cognitive behavioral group therapy (CBT) or a no-treatment control group. The CBT intervention

consisted of eight weekly sessions (2hr/wk) led by two therapists with one being a licensed psychologist. A manual was given at the start of the intervention as well as handouts and homework assignments to be completed each week. Cognitive techniques, specifically identifying and challenging maladaptive thoughts were introduced in the first session, with behavior techniques such as coping, deep relaxation, problem solving and goal setting introduced in the second session. All group meetings began with one hour of discussion focused on the cognitive homework assignment and the second hour on discussions of topics for that day. Topics covered included managing depression, effective communication, self-esteem, managing anxiety, self-image, interpersonal relationships, and dealing with anger.

Efficacy of the group was measured through the use of the Profile of Mood Scale (POMS), and the Coopersmith Self-esteem Inventory. Assessments were given prior to the intervention, post intervention and at a 3 and 6 month follow up. Results for the treatment group indicated a reduction in depression and total mood disturbance with improvements seen in self-esteem when compared to the no-treatment control. However, no differences were found at the three and six month follow-up indicating short term improvements (Edelman, et al., 1999a).

Subsequent to the finding that the cognitive behavioral support group showed improvements on mood, depression and self-esteem, Edelman, Lemon, Bell, and Kidman (1999b) assessed the sample on survival time when compared to the control group. One hundred and twenty-one participants from the original study (Edelman, et al., 1999a) were assessed five years post intervention with survival calculated from the date of entry into the original study. It was found that participants did not receive any survival benefits when compared to those in the control sample. As with Cunningham, et al., (1998) the lack of survival benefits was attributed to

the physical status of the participants and the multitude of variables that can influence the disease progression.

An additional study on women with metastatic breast cancer was conducted to assess mood, quality of life and adjustment to cancer. Edmonds, Lockwood and Cunningham (1999) conducted a randomized trial on 66 women diagnosed with metastatic breast cancer. These women participated in either a weekly (2hr/wk) 8 month long term group intervention or a no-treatment control. The intervention included a group of approximately 8 women and two leaders, a clinical psychologist and a co-therapist, either a psychology doctoral student or social worker. The group consisted of three components. First were the weekly meetings similar to Spiegel, et al., (1981) where topics of support, problem solving, death, and emotional reactions were discussed. Matched with these topics and weekly meetings was the second component, 20 cognitive behavioral homework assignments (to be completed at home and then discussed in the next session) that covered topics regarding monitoring thoughts and behaviors, thought and behavior replacement and resistance to change. The final component was a weekend coping skills training that all participants were asked to attend. This training included relaxation and mental imagery to help in stress reduction, positive affirmation and goal setting.

Results from this intervention were measured through the use of questionnaires including the Profile of Mood States, Functional Living Index for Cancer, Social Support Questionnaire, the Mental Adjustment to Cancer Scale, and the Rationality/Emotional Defensiveness Scale. After assessment at baseline, 4mths, 8mths and 14mths, little difference was found between the control and intervention groups. The long term group therapy did not significantly differ from the control group on mood, quality of life, social support, or repression. The only differences that

were reported included greater anxious preoccupation and less helplessness over time in the treatment group versus the control participants (Edmonds, et al., 1999). This indicates that the intervention may have led to some anxiety but contributed resources to reduce the feeling of helplessness. Overall the long term group intervention does not seem to create significant psychological changes within the population of women with metastatic breast cancer.

Long term group therapy for women with metastatic breast cancer was examined in an additional study consisting of weekly meetings for one year. Classen, et al., (2001) conducted a randomized trial of 125 women to assess the efficacy of a supportive-expressive group intervention verse a control group of educational material only. The intervention consisted of weekly 90 minute sessions conducted by two leaders (i.e. psychiatrist, psychologist or social worker). The sessions were unstructured and room for emotional expression was a main goal. Leaders of the group introduced five themes that were open for discussion among group members. Themes included fears of dying and death, reordering life priorities, improving support from friends and family, self and body image, and improving communication with physicians. In addition to the themed discussions, each session was concluded with a self-hypnosis exercise.

Assessments for this intervention were given post baseline and every four months. Measures included the Profile of Mood States and the Impact of Event Scale. Results indicated that the intervention led to a significant decline in trauma stress symptoms when compared to control. Secondary analysis (excluding assessments within one year of the participant's death) showed significant decline in total mood disturbance and trauma stress symptoms (Classen, et al., 2001). These results support the utilization of an unstructured, supportive expressive, long

term group for women with metastatic breast cancer. Specifically this study shows the improvements that can be made in trauma symptoms.

Long term supportive-expressive group treatments are again examined in a study of 235 with women with metastatic breast cancer (Goodwin, et al., 2001). This intervention consisted of one year of weekly 90 minute sessions with 8-12 participants in each group and two leaders (i.e. psychiatrist, psychologist, social worker, or nurse clinician). The group was similar in the unstructured nature to Classen, et al. (2001) with the members able to openly discuss themes including, effects of the illness, treatment, self-image, relationships with friends and family, coping and communication.

The main outcome measure for this group intervention was survival time, however, psychosocial functioning was also established through self-report, pre and post intervention. Results show no significant difference in survival time when compared to the no treatment control group. However, a trend toward improvement of psychological symptoms and less pain was found for the intervention group with those more distressed as baseline showing greater psychological improvements (Goodwin, et al., 2001). As with previous research assessing survival time, it is difficult to draw a direct link between a group intervention and increasing life time due to the multitude of variables that are different for each participant despite the similarity in diagnosis.

Geise-Davis, et al., (2002) again, examined the use of a supportive expressive group treatment for women with metastatic breast cancer by assessing changes in emotion regulation. One hundred and twenty-five women with a diagnosis of Stage IV breast cancer were randomly assigned to either a treatment (supportive expressive) group or a control (educational materials

only) group. Participants in the treatment group met for weekly meetings (90min/wk) for one year. The intervention was very similar to those that had been conducted previously (Classen, et al., 2001; Goodwin, et al., 2001) with a two leader, semi-unstructured format. Themes that were introduced into the sessions include social support, expressing emotions, death and dying, reordering life priorities, friends and family, self and body image, communication with physicians and learning self hypnosis. The main goal for the study was to examine the efficacy of this intervention on emotion regulation including suppression of negative affect, repression, restraint, and emotional self efficacy. Measures were taken post baseline and every four months.

Results from the utilization of a long term supportive expressive group showed a significant decrease in primary negative affect and an increase in restraint of aggression, inconsiderate, irresponsible and impulsive behaviors when compared to control. However, changes in repression and emotional self-efficacy were not found. The results indicate that a supportive expressive group for this population can increase the expression of emotion without participants becoming hostile towards their situation (Geise-Davis, et al., 2002).

The more recent literature on group treatments specific to women with Stage IV breast cancer reveals a follow up study from Spiegel, et al., (1989) which found an increase in survival time as a result of a supportive expressive group treatment. Spiegel, et al., (2007) conducted an additional study utilizing the same structure from previous works (Spiegel, et al., 1983; Spiegel, et al., 1989; Classen, et al., 2001; Goodwin, et al., 2001; Geise-Davis, et al., 2002) in an attempt to recreate the increase in survival time. One hundred and twenty-five women with confirmed metastatic breast cancer were randomly assigned to the treatment or control. Subsequent to the one year of treatment, survival time was assessed 14 years later with a mortality rate of 86%.

Results indicate that there was no significant difference between the treatment and control conditions with median survival times of 30.7 months and 33.3 months respectively. These results show an inconsistency between the Spiegel, et al., (1989) study and this replication study. Researchers state that these findings were more closely matched to the previous examinations of this type of supportive expressive group treatment for women with metastatic breast cancer, whereas an increase in survival time was not found.

The final study that is specific to a Stage IV population was conducted, again, utilizing the same supportive expressive group therapy that was manualized by Spiegel and Classen (2000) and utilized in much of the previous research (Spiegel, et al., 1983; Spiegle, et al., 1989; Classen, et al., 2001; Goodwin, et al., 2001; Giese-Davis, et al., 2002; Spiegel, et al., 2007). This study was designed specifically to examine the effect that this group intervention has on pain and suffering, frequency of pain, and degree of constant pain. One hundred and twenty-four women with metastatic breast cancer were assessed at base line and four month intervals. Results indicated that participants reported a significant decrease in the intensity of pain and suffering over time. However, there were no significant differences in frequency of the pain, nor amount of constant pain experienced by the women. Since this group treatment includes a self-hypnosis at the end of each session, it was found that those who were more highly hypnotizable did gain greater benefit from the self-hypnosis than those that were not. Overall, the supportive expressive group and use of self-hypnosis showed some evidence that this form of treatment can help in the management of the pain that is experienced.

Conclusions

The literature specific to interventions for women with Stage IV or metastatic breast cancer illustrate positive outcomes for not only psychological distress but also some physical symptoms of pain. The supportive-expressive group structure is interwoven throughout the literature and utilized in all but one of the groups conducted. This group format has shown positive outcomes in decreasing psychological distress and mood disturbance and in increasing participants' ability to cope with pain symptoms. Cognitive behavioral techniques were also utilized and found to have short term benefit on mood, depression and self-esteem.

Outcome measures utilized within this literature include examinations of distress and pain but overwhelmingly there is a focus on survival time. Many of the articles concentrate on attempting to increase the survival time of women with metastatic breast cancer through the use of a group intervention. The research shows that this endeavor is difficult to prove and that the multitude of variables influencing the illness and the individual, create too much variation to make a direct link between survival and intervention.

The literature examining groups for women with metastatic breast cancer has shed some light into how interventions influence this population and the outcomes that can come from participation in a group setting. However, the research specific to this population is limited and an understanding of the needs and experiences of these women is needed. Overwhelmingly the voices of these women are underrepresented in the literature. This limitation in the research is detrimental in the creation of interventions that meet the specified needs of this population, but also that address the quality of life issues that these women face. As has been seen, women with metastatic breast cancer have no hope for a cure, but hope for an increase the quality of the life that they have left is attainable and necessary for this population.

CHAPTER 3: METHODOLOGY

Research Design

Overview of approach. This study investigates women with diagnosed Stage IV, metastatic breast cancer. The meanings and experiences of this group of women were examined to gain an understanding of the needs of this population and how to successfully understand factors that contribute to improved life quality. The narratives of these women describe their cancer experience, how they view life, how they view death, their current quality of life, and information regarding their quality of life needs.

The design of this research project is qualitative, guided by the phenomenological approach. Phenomenology allows the researcher to obtain rich data in an attempt to increase understanding of a phenomenon shared by a group, in this case the life experiences of women living with diagnosed Stage IV breast cancer. Women with Stage IV breast cancer have great variation in experience from one individual to another. For this reason the design of this study needs to leave room for expression of the personal variations, while simultaneously creating a comprehensive understanding of the individuals' shared experiences.

Qualitative research. Qualitative research is a type of research that is utilized to gain a deeper understanding of individuals or groups and the meanings that they attribute to a social or humanistic problem (Creswell, 2007). The problem in question for this study is the experiences of women living with Stage IV breast cancer. Qualitative research will capture the voices of these women and lead to an enrichment of the literature and a call to action for the development of best practices to address the needs of this population.

There are several tenets of qualitative research that are well suited for this proposed study. First, within the framework of qualitative data, the researcher is a key instrument throughout the process (Creswell, 2007). The researcher is the collector of data and does not depend on questionnaires or instruments to assess the experiences of the sample. In contrast, the researcher utilizes methods of interview and direct contact with the population to create an in-person experience of the research participant along with a continuum of gathering and interpreting the data.

The next tenet of qualitative research that supports the research inquiries of the proposed study is the utilization of inductive reasoning. Inductive reasoning is a “bottom-up” approach by organizing observed data into themes and categories that generate an understanding of a specific situation or problem (Creswell, 2007). The main goal of induction is to build a theoretical explanation from repeated observations of a specific circumstance (Daly, 2007). The proposed study will take this approach by utilizing in-depth interviews to create a deep understanding of the lived experience of Stage IV breast cancer.

Qualitative research has a keen focus on the capturing of participant meanings (Creswell, 2007) which is in line with the theoretical tenets of the proposed study. The utilization of these theoretical tenets will give the researcher background information on this population and a broad understanding of terminal illness, before directly observing women with metastatic breast cancer. The researcher will begin with the broad theoretical lens previously outlined and then gather data from a specific sample to enhance the knowledge and understanding of the experience of stage IV breast cancer. Qualitative research values the process of capturing the participant meanings of a certain situation (Creswell, 2007; Daly, 2007). This principle alone supports the use of this

form of research for the proposed study. The main goal of this study is to understand the experiences and meanings attributed to living with terminal breast cancer. Qualitative research is needed to depict the voices of women with Stage IV cancer and to create understand of the needs and struggles of this population.

Phenomenology. There are several different techniques that can be utilized in qualitative research. Phenomenology is the approach that is utilized in this study. The purpose of phenomenology is to investigate the subjective lived experiences of a group related to a particular phenomenon and how they make meaning within their subjective world contexts (Daly, 2007). This approach will be applied to evolve a collective experience through the emergence of characteristics and themes shared by the participants examined. Phenomenology is rooted in the philosophy of how objects, actions and events appear in the consciousness of a subject (Daly). Alfred Schutz (1971) took this approach from philosophy to social science by identifying a two-step process to gain a “sympathetic understanding” of everyday life. First, individuals interpret their world within their specific context, biography and sphere of relevance. Second, social scientists observe and record the ways in which these individuals do this and in the process, interpret their own meanings to the collective, subjective, and observed meanings of the individuals (Daly). Intersubjectivity is a key concept within phenomenology. Intersubjectivity is the idea that in every reality there are subjective perceptions, however, there are also common elements and shared meanings within that reality. The current study applies this concept by observing and recording multiple subjective lived experiences, interpreting them through a research lens, and creating meaning in the shared experience of the particular phenomenon.

The phenomenology approach is ideal in the examination of the lived experience of Stage IV breast cancer. Through the exploration of the research questions and the use of in-depth interviews, the current study will produce an understanding of the experience of Stage IV breast cancer and how the women within the study experience their lives after this diagnosis and how they create life quality in spite of their situation. Additionally, this research will be utilized to inform new interventions for this population, educate those who are currently conducting psychosocial interventions to better meet the specific needs within the experience of Stage IV breast cancer, and educate those who work closely with this population (oncologists, nurses, marriage and family therapists, social workers, and the like).

Researcher bias. One the most valued principles in the phenomenology approach is “bracketing” of reality (Daly, 2007). Bracketing refers to the suspension of any judgment of the reality being examined in order to experience the reality as the subject experiences it. The researcher must be aware of any bias/judgments that they bring to the observations and set them aside, so that they do not influence the data collection. Therefore, it is of paramount importance that all biases are clearly expressed and all efforts are made to achieve unbiased observations.

The researcher of the proposed study holds two main biases in regards to the data collected. First, due to the undertaking of reviews of previous research, it is the belief of this researcher that women with Stage IV breast cancer have a different experience than those with other stages of breast cancer. Having examined much of the psychosocial intervention research in this area the researcher holds the judgment that due to the severity of illness, incurable nature of the disease, and lack of interventional resources specific to this population, that these women should be placed in a different category than those with other forms of breast cancer. The

researcher was diligent in compartmentalizing this belief when observing women with Stage IV breast cancer. To address this judgment, the researcher made every effort to take a neutral stance with this population, as opposed to the researcher presenting this subjective opinion to the participants. Prior to each individual interview, the researcher took time to reflect on this bias as an effort to bracket and maintain a neutral stance.

Additionally, it is the belief of this researcher that group interventions are beneficial for this population. Having examined much of the efficacy research in the area of psychosocial interventions for women with breast cancer and having read the multitude of benefits that have been found, the researcher had to be diligent in compartmentalizing this belief when observing women with Stage IV breast cancer. There is potential that some, if not all, of the women within this study may hold different beliefs regarding the benefit of group interventions. Some of the women may have had negative experience in the past and may share these negative thoughts with the researcher. To address this bias the researcher made every effort to take a neutral stance on group interventions and focus more on gathering the experiences, both positive and negative of the participants within the study. Prior to each interview the researcher spent time bracketing this bias in an effort to not impose this perception onto the participant. Dialogues with the chair of the dissertation committee were continuous to check in with this bias and every effort was made to avoid bringing this into the phenomenology approach.

Procedures

The study included individual interviews with women with a diagnosis of Stage IV breast cancer. The description of goals is as follows:

To explore the subjective experiences of women with a diagnosis of Stage IV breast cancer through 10 individual interviews.

1. To understand the metastatic breast cancer experience from the time of diagnosis to the time of the interview.
2. To gain an understanding of needs specific to this population of women including physical, psychological, spiritual, and social.
3. To gain understanding of how social supports influence their personal experience of cancer.
4. To gain an understanding of the participants' thoughts regarding life and death when facing their own mortality.
5. To gain understanding of the quality of life factors in this group of women and the contextual and support factors that increase quality of life or serve as barriers to quality of life.

Sampling procedures.

Determining sampling sites. The participants for this study were recruited from multiple sites. The sample of women with a diagnosis of Stage IV, metastatic breast cancer, were found within the United States, and recruited through hospital settings, oncology offices, and a blog site specific to this population.

Recruitment. The recruitment process for this study began with contacting three sources located in the South Eastern region of the United States. These connections were as follows:

the President of Georgia Center for Oncology Research and Education (CORE), the head oncologist for Atlanta Cancer Care and principle investigator for the Atlanta Regional Community Clinical Oncology Program, and the Cancer Care Center of Tuscaloosa, AL.

The first contact with the sources consisted of an email sent to each individual introducing the researcher as the primary investigator and introducing the current research. A summary of the proposed study and a section specifically outlining the population of inquiry were included within the emails. Following the emails, phone calls to each of the contacts were made by the researcher to form a more personal connection with the recruitment resources and to answer any questions from each contact. The researcher then scheduled a face to face meeting with each contact to further discuss the project and methods for recruitment.

Once an agreement was made between the researcher and contact person, informational flyers were distributed to each sampling site outlining the study and inclusion criteria (see Appendix B). The flyer gave clear direction to anyone interested in participation related to how to contact the researcher directly by phone or through email. Included in the flyer was a description of the study, inclusion criteria, and the description of an incentive of \$25. The flyers were distributed by the contact person to those who met the inclusion criteria and posted in offices where the population frequented (e.g. oncology offices, bulletin boards in hospital).

Additional recruitment methods were taken through the use of internet resources and one blog specific to women with metastatic breast cancer called www.inspire.com. This site offered blogs specific to many different illnesses and was a resource that this participant utilized. The researcher went onto this site and created an account. A post was then made onto the blog giving women the same information that is on the flyer distributed to physical recruitment sites. The

women were, again, asked to contact the researcher by phone or through email if they were interested or had any questions.

When participants contacted the researcher by email or phone, they were then assessed based on inclusion and exclusion criteria in determining whether or not the person was a potential candidate. If inclusion criteria were met, a verbal consent to participant was gained and an informed consent was sent through the participant's email. The informed consent included information regarding the expectations of the participant and the research being conducted. It also included instructions to sign the form and how to send it back to the researcher via email or U.S. mail (see Appendix C). Once the informed consent was signed and sent back to the researcher, availability of the participant was assessed and either a face to face meeting or phone interview was scheduled depending on the location and transportation limits of the participant.

Inclusion and exclusion criteria. Inclusion and exclusion criteria for the proposed study were utilized so that all participants accurately represented the population of interest. Inclusion criteria included that the participant must be a) a woman b) have a current primary diagnosis of Stage IV breast cancer. A breast cancer diagnosis can either begin with a Stage IV diagnosis or develop into a Stage IV diagnosis over time. All women included had a Stage IV diagnosis.

Women were excluded from participation within the study if, a) they did not possess a Stage IV diagnosis, or b) English was not their primary language. Due to the diverse population within the South East, it is important to make the English language distinction as there may be potential participants that utilize English as their second language.

Sample description. The current study consists of 10 participants located across the United States. Five participants were clustered within the South East of the US (Alabama and

Georgia). The remaining 5 participants were sampled from a blog website and were located on both the east and west coasts of the country (see Table 3.1). Participant ages ranged from 46-80 with a mean age of 58. At the time of the interview the participants had lived with Stage IV breast cancer between 1.5 and 14 years. Four participants had never had a previous diagnosis of breast cancer, while the remaining 6 had different breast cancer experiences previously, but never a previous Stage IV diagnosis. Nine of the 10 participants were Caucasian and one labeled herself as Italian and Japanese. Three of the participants had no connection with a family of choice (e.g. single and no children). Participants had varying spiritual affiliations including Methodist, Protestant, Episcopalian, Christian, Catholic and Buddhist. Three of the participants did not have any spiritual affiliation. Regarding employment status, two of the participants were working full time, three were working part time, two were retired, and three reported being unemployed (see Table 3.1).

Table 3.1: Demographic Information

#	Age	Race/Ethnicity	Date of Stage IV Diagnosis	Previous Cancer Diagnosis (Type/Date)	Immediate Family Members	Age of Family Members	Employment Type	Employment Status	Spiritual Affiliation	Highest Level of Education
1	80	Caucasian	Dec. 07, 2012	None	Husband Son Son Daughter Granddaughter	Deceased 58 55 51 20	Real-estate Broker	Retired	Methodist	Associates Degree
2	66	Caucasian	2011	Stage II/2001	Husband Daughter Son	72 34 30	Organ player for Church Bank Teller	Unemployed	Protestant	Bachelors Degree
3	55	Caucasian	November, 2011	Stage I/2007	Husband Daughter Daughter	57 25 28	Substitute Teacher	Employed Full Time	Catholic	Masters Degree
4	47	Caucasian	October, 2003	None	None		Dog Walker	Employed Part-time	None	Some Grad School
5	55	Caucasian	June 15 th , 2012	Stage IIIC/2008	None		Secretary at University of Washington	Unemployed	Buddhist	Bachelors Degree
6	50	Caucasian	2000	1988 and 3 reoccurrences of varying stages.	Husband Son Daughter Daughter	54 26 23 20	Teacher Assistant	Employed Full Time	None	Associate Degree
7	59	Caucasian	January 1, 2009	None	Son	31	Store-All Storage Manager	Retired	None	2 years of College
8	46	Italian and Japanese	January, 2010	Stage IIB/IIIC/ Jan. 2007	Husband Daughter Daughter Daughter	52 21 18 16	Lunch Worker at High School	Employed Part-Time	Catholic	High School
9	69	Caucasian	February 15 th , 2011	Mentioned previous diagnosis but Stage not specified (Not IV)	Husband Son Son	68 34 32	Teacher	Employed Part-Time	Episcopalian	Post Graduate
10	50	Caucasian	May, 2011	None	Niece (Lives with) Niece (Lives with)	19 17	Advertising Sales	Unemployed	Christian	Some College

Data collection.

Individual semi-structured interviews. The study design includes 10 individual interviews with women with a Stage IV breast cancer diagnosis. Individual interviews are widely utilized as a way to gain information in qualitative research. Specifically, with the approach of phenomenology, interviews are conducted as a way to elicit detailed descriptions of a certain reality (Daly, 2007). The ways in which an interview is conducted also depends on the methodology that is being used in the research. In a phenomenological approach, it is essential to gain a detailed description of the shared experience (Daly 2007). To achieve this, a semi structured interview was utilized. “In many qualitative interviews, the researcher begins with a set of question that have arisen from a reading of the literature or an understanding of preexisting theory,” (Daly, 2007, p. 145). Based upon the theoretical framework described (Samson & Siam, 2008; Wright, 2003), a collection of 22 interview questions were created to address all aspects of the experience of Stage IV breast cancer. An interview guide was created that included an introductory statement and the interview questions (see Appendix E). As the interviews progressed some questions were asked differently, probing questions were added, and some questions were dropped due their repetitive nature.

Once contact had been made between the researcher and potential participant, and it was established that the woman met inclusion criteria, and the informed consent form had been signed, the interview took place. Depending on the location and physical health of the participant and the location of the researcher, it was decided whether a face to face interview was possible, or whether a phone interview was preferred. Only 2 of the interviews were conducted face to face. These interviews were conducted in a conference room located within the Cancer Research Center of Atlanta. The additional 8 interviews were completed via phone. The interview began

by the participant answering several demographic questions (see Appendix D). After demographics were completed the interview questions began. Once the interview was completed the researcher mailed the participant a \$25 Visa Gift Card as a token of appreciation for their participation.

Data preparation. All interviews were audio recorded using a hand held recorder either placed on the table between the two individuals or placed near the speaker on the telephone utilized by the researcher. Once the interview was recorded, the audio WAV file was transferred onto the researcher's personal password protected laptop. Each interview was saved under a randomly assigned participant number (1-10). The interviews consisted of approximately 14 hours of audio recorded data. The researcher then hired an independent transcriptionist to transcribe the audio files into text files. The transcriptionist had no identifying information attached to the files, other than the randomly assigned numbers. The transcriptionist was also asked to sign a confidentiality statement to ensure that all data was secure (see Appendix F).

Data analysis. The data analysis was conducted in adherence to the procedures of the phenomenology approach. Analysis included the use of the seven step process outlined by Colaizzi (1978). The first step in the analysis was to read the transcribed participant narratives in order to acquire a feeling for the individual experiences and to understand them fully. The second step is to extract any significant statements by identifying key words and sentences that related to the phenomena that was being examined. The third step was a process of identifying meanings to these significant statements within the narrative, thus creating a set of meaning units. Fourth the process was repeated for all participant narratives and recurrent meaning units were clustered to create themes within the data. These were validated by returning to the data to

check interpretation. The researcher conducted two detailed searches for meaning units prior to clustering into themes. The fifth step involved the integration of the themes into a way that resulted in a rich description of the phenomena. Sixth, the themes were placed into a structure that offers an explanation of the experience. The final step involved the researcher returning to the participants to conduct further interviews in order to cross check interpretation and to elicit their opinion on the analysis. The current study utilized the first 6 steps of these procedures in order to create an understanding of the experience of Stage IV breast cancer in regards to quality of life and needs. The seventh step involves bringing the data back to the participants for feedback, this was not conducted within this study.

Role of the Researcher

Throughout the process of this proposed research study, I (the researcher) was central to both the data collection and data analysis. For this reason I aimed to continuously reflect on my biases, background, and experiences in an effort to keep them separate from the data analysis process. Through bracketing, the writing of memos, constant reflection and discussions with the head of my committee, becoming familiar with the culture prior to engagement, gaining a thick description of the data and having a deep familiarity with previous research on the population, I made every attempt in understanding the lived experience of women with Stage IV breast cancer.

Trustworthiness

The trustworthiness of research can be broken down into four distinct criteria (Miles & Huberman, 1994); confirmability, dependability, credibility, and transferability.

Confirmability. Confirmability is the process of achieving neutrality of the findings and reducing influences of biases. Specifically, I utilized reflexive memo writing as a form of commentary throughout the proposed study specific to the biases and personal emotions I brought to the project. Memo writing is the process of writing down thoughts, hypotheses and observations about the relationships among the data. In the current study, memos are used as a bracketing technique to create constant feedback between the researcher and the data. Specifically there are different forms of memos that can be written within this process (Strauss, 1987); textual memos: how one thinks about the data or codes that are emerging; observational memos: memos focused on the contextual observations within the research; conceptual/theoretical memos: thoughts regarding the creation and interrelationships of the categories; operational memos: practical thoughts and reminders such as questions to ask or sampling strategies; reflexive memos: observations of the researcher and any personal thoughts or feelings that emerge throughout the process. This grouping of memos was utilized through the process of data collection and analysis. These memos were utilized as an additional resource in the researcher's process of bracketing.

By utilizing detailed reflexive memos to conduct bracketing, I made a constant, conscious effort to understand where biases lie and how they could influence the data. Additionally, the memos gave a venue to express personal emotions regarding the data being collected and analyzed so that these emotions could be utilized productively to help the participant's voices be heard as opposed to projecting my own emotional needs and reactions onto the data.

Dependability. Dependability in qualitative research suggests that the process of the research is consistent and stable over time. To reach dependability, methodology must be clearly

described for the possible duplication of the research (Morrow, 2005). Dependability was addressed by the researcher through detailed description of the methods used, how meaning unit and themes arose, through memo writing and the use of reflective commentary with the head of the research committee.

Credibility. Credibility of research refers to the idea that the data observed represents the authentic picture of reality. This can be established utilizing several differing techniques. The current study utilized established phenomenological research methods, gaining a cultural understanding of the population observed prior to data collections, examining previous research findings, and collecting a thick description of the phenomena (Shenton, 2004). First, the researcher utilized established phenomenological research methods highlighted by Colaizzi (1978). Meaning units and themes were established through two detailed examinations of the data (see Table 3.3). Prior to data collection I examined a breadth of previously published literature on breast cancer and literature specific to Stage IV. Additionally, I read two non-fiction books on the experience of cancer (*It's Not About the Hair: And Other Certainties of Life and Cancer* by Debra Jarvis and *Any Day with Hair is a Good Hair Day: How to get Through Cancer and Get On With Your Life* by Michelle Rapkin) and had many conversations with individuals who worked directly with patients of breast cancer, including oncologists, nurses and those who work in the field of cancer research in an attempt to create an understanding of the population prior to questioning participants on their lived experience. In an additional attempt to reach credibility I elicited the participation of 10 different women from across the United States in order to gain a wide range of experience and depth of understanding. Each woman has had the disease for a different length of time, has differing personal circumstances and has a unique

subjective experience. By embracing the differences among the sample, the researcher was able to gain an authentic description of the reality of living with Stage IV breast cancer.

Table 3.3: Meaning Units and Themes

Meaning Units: Level 1	Meaning Units: Level 2	Themes
Family	Supporting the Woman with Stage IV BC	Relationships
	Family Reactions to the Disease	
Finances	Leaving Work	Financial Struggle
	Insurance Struggles	
Cancer Education	Information from Doctors	Need for Education
	Relying on Self Research	
Past Experience with Illness	Past Cancer Diagnosis in Self	Personal Characteristics
	Past Experience with Terminal Illness in Family/Friends	
	Age	
Community Support	Close Friends	Relationships
	Having a Community (church, group involvement, etc.)	
Stage IV Specific Experiences	Mortality	

Table 3.3 (cont'd)

	Reality of Illness	Making Meaning
Physical Struggles	Side Effects from Treatments	Body Deterioration
	Fear of Future Body Deterioration	
Emotional Reactions	Attitudes Towards Self	Making Meaning
	Attitudes Towards Death	
	Psychological Reactions	
Spirituality	Religion and Prayer	Faith
Support Groups/Therapies		Need for Connection
Quality of Life Statements	Need for Connection to Others with Stage IV	Creating Quality in Life
	Need for Information, Education, and Advocacy	

Transferability. Transferability refers to the ability to apply the observed research to others in similar context. Within qualitative research, data collected cannot be generalized to other populations or other settings, however, transferability can be reached through the inclusion of detailed information about the study being conducted (Morrow, 2005). The current study provides documentation of participants, research methods, the investigator, and the contextualization of the study. Additionally, the current study relies heavily on the voices of the

participants, through quotation, to enhance transferability. Although the current study will not attempt to generalize results to all women with a Stage IV diagnosis of breast cancer, it will create a description of the common themes and categories that arise from the participant experiences. This can then be applied to those in a similar situation in an attempt to bring more specified resources to the population.

Considerations of Human Subject Issues

The current study adheres to all procedures necessary in reducing the risk to the research participants. Prior to the initiation of the research, approval from the Institutional Review Board of Michigan State University (IRB) was gained. The application for the IRB thoroughly outlined all procedures of the study and addressed all risks to human subjects.

CHAPTER 4: RESULTS

The purpose of this study was to examine the lived experiences of 10 women with Stage IV breast cancer. The purpose of this chapter is to present the themes the women described related to living with a Stage IV breast cancer diagnosis. I set out to answer the following research questions: “What are the lived experiences of women with Stage IV breast cancer, what helps them to live with this diagnosis, and what contributes to and what impedes, their optimal quality of life? In the process of data analysis, eleven first level meaning units emerged following the first review of the transcribed interviews. Additionally, 20 second level meaning units were developed from the original 11 during the second detailed review of the transcribed interviews. Utilizing the voices of this population, these themes are described. Finally, an explanation of the lived experience of Stage IV breast cancer in the context of creating optimal quality of life is presented.

I set out to answer the research questions and was guided in the phenomenological analysis by the theoretical framework of Samson and Siam’s Comprehensive Task Model (2008). Several major themes arose and these included personal characteristics, reaction and acceptance of diagnosis, reality of the disease, body deterioration, mortality, needs, relationships, faith, life purpose, financial struggles, making meaning, and quality of life. These themes combine to describe the specific experience of Stage IV breast cancer. Themes are presented and organized following the theoretical model utilized within this study.

Personal History and Social Context

Samson and Siam (2008) explain that personal history and social context include background and personal characteristics, event-related factors and physical and socio-cultural environment. These aspects of individuality influence how a person views their illness. Within the current sample, each participant brought a unique perspective that influenced the overall lived experience of Stage IV breast cancer. The individual narratives were created through an individualized lens, where differences among individuals in the sample shaped how the women experienced their cancer. Among the descriptions, age, ethnicity, length of disease presence, previous cancer diagnosis, family make up, employment status and type, spiritual affiliation, level of education and location, and past experience with a severe illness in a family member, many differences were observed. In order to capture the lived experience of each woman, I provide next a thick description of each participant including a description of characteristics which stood out for the women as having the greatest influence on how they viewed their cancer experience. The voices of the women are presented regarding these three characteristics to further explain each individual narrative and how Stage IV breast cancer was viewed by each.

Participant 1. Participant 1 is the eldest of the participants at 80 years old. She is a Caucasian woman, from Northport, AL, who has had a diagnosis of Stage IV breast cancer for approximately two years. She has had no previous cancer diagnosis, prior to Stage IV. Her husband had passed away two years prior to cancer and all of her children were adults with their own families. Participant 1 is close to her three children and their families. She holds an associate's degree and is a retired real-estate broker. She retired due to her age and not her disease. Participant 1 is religious and labels herself as Methodist. She has a strong community linked to her church. Overall she has a positive attitude on life which may also be related to her age. The age of this participant led to many differences in her personal circumstances with

cancer. At the age of 80, she had a unique view of life which influenced how she viewed her cancer:

“No, I was not devastated [regarding having Stage IV breast cancer], because I am quite aware that we are temporary here on earth and we are all going to die. At my age I have had such a full life.”

“I don’t sit around and dwell on the fact that I have cancer. It has not devoured my life. It has devoured a lot of my activities, but at age 80, I guess you start to slow down some anyway, I hadn’t started, but I guess I have now.”

Participant 1 could look back and see the fullness in her life. She sees ways in which her Stage IV cancer slows her down physically but did not seem to be able to separate those ailments from her age and physical body slowing down naturally. This gave her a perspective where the cancer could not be blamed for all her physical struggles. Due to her age, she also had the privilege of working to retirement and choosing to retire. She was also able to see her children grow into adults and to have the experience of being a grandmother. Combine these characteristics of her life gave her the response of not being devastated that she was living with Stage IV breast cancer.

The past experiences that she had had with her husband also created uniqueness in her own experience with cancer. She both had the comfort in having resources that she had utilized previously with her husband, but also had the difficulty of her children living with another parent with cancer and facing her possible death:

“I was dealing with a husband who was not well at all and then when they finally diagnosed me with cancer, he had deceased...to have been already very much involved in the cancer center with my husband and they were just wonderful to him and so, I went immediately to them.”

“There was not any doubt in my mind that that is where I would go for the treatment. It was very difficult to tell my family, because we had just gone through all of this with him.”

“But, like I said, they already had been in the throes of all of this or it might have been much harder for them. And of course, it was hard because they had just lost their father. So I guess one of the pluses is that he did not have to go through this with me so I consider that one of the blessings and there have been many, many, many blessings and the children are the greatest ones of course.”

Participant 1 describes having a long life and how much of her slowing down is not only due to her cancer but her age. Additionally, she describes her past experience with her husband as both positively influencing her own experience through feeling more prepared for how to approach her cancer treatment, but also a negative influence on her family who had just lost their father and had lived through his cancer. These factors created a lens that enabled Participant 1 to experience her Stage IV diagnosis with a sense of preparedness regarding her own mortality and how she would react and adapt to her cancer diagnosis.

Participant 2. Participant 2 is a 66 year old, Caucasian woman from Benton City, Washington. She has a husband and two adult children. She has had one previous experience with breast cancer, in 2001 where she was diagnosed with Stage II. She has held a Stage IV diagnosis for 3 years. Participant 2 was extremely well read. She spent a great deal of her time researching alternative medicines for her treatments as she held strong feelings that Western medicine was not always the best choice for treatment. She had witnessed a lot of illness and death as a result of her job as an organ player at her church (she played many funeral services as well as church services). Participant 2 stated that she was Protestant and strong in her faith. Additionally, she had a neighbor who had dealt with severe illness, and she had observed multiple illnesses in her family. These experiences helped shape her views of Stage IV breast cancer:

“The gal across the street had breast cancer about the same time I did, but it was a small cute little street you meet at the mailbox, and come to find out we found out, we had breast cancer at the same time. Her husband, the minute she came home with the diagnosis said, ‘I can’t handle this,’ and left her. So that was my first and in my face experience because I was just out of treatment myself so I hadn’t paid that much attention to other things.”

“...so I hear stories of all sorts of things, of all sort of things that have happened and I have seen a great deal of separation and so the um, um, that was one thing that I was committed to not doing myself and my family was not like that, grandma with stroke, grandpa with dementia, we were not a perfectly healthy family, but we still get by. Uncles and aunts that do things that gave up their life which meant giving up some of our lives. So that’s the core of me but, because of my semiprofessional job I have seen a lot of, for whatever reason, people are fractured and splintered because of cancer.”

Participant 2 had observed a lot of hurt and heartache around having cancer and how it affects individuals and those close to them. She had also experienced seeing strong support when members of her family were ill. Based on these experiences she knew the importance of having her family support her, but was understanding that not all people react with support.

Participant 2 also alluded to her life stage in regards to how she views her cancer experience:

“...my kids are grown and I am seeing my grandkids are being raised well and healthy and all that stuff. I know that I will see them in heaven...”

Due to her age, she had been able to experience her children growing up and them having kids of their own. She was a grandmother and knew that her grandchildren are being raised well. The statement “I know I will see them in heaven,” gives almost a sense of satisfaction with being able to have seen this much of their lives already.

Her own personal past experience with breast cancer also influenced how she accepted her metastatic diagnosis and how her family responded.

“I forgot to tell my husband. I mean I forgot until dinner time. So, I had it at nine in the morning, but then I was like oh what about this bill to pay, and how his day was. Then sitting down to eat, I was like oh by the way, cancer metastasis to my body and his fork went down. He cried and um. But, I said there is stuff out there like there was before. So, it was like um, how I felt was, I knew they would feel this way because they did this the first time. They adjusted; they didn’t stop their lives, because they are all very busy. That’s how I raised them. I needed them to have their life.”

Participant 2, having experienced breast cancer previously, describes a preparedness in herself and in her family. This preparedness influenced how she viewed her cancer.

Participant 3. Participant 3 is a 55 year old, Caucasian woman living in Atlanta, GA. She has a husband and two daughters in their twenties. She had one previous breast cancer diagnosis of Stage I in 2007. Participant 3 has been living with her current diagnosis for 2.5 years. She was working full time as a substitute teacher and held a Master’s degree. Participant 3 labels herself Catholic but does not feel very close to that religion and has more of a personal spiritual connection than a connection to religion. She is also a very active woman and runs long distance and was recently training for a marathon.

Participant 3 struggled with her current diagnosis. Her first experience with breast cancer in 2007 made it more difficult to accept her current diagnosis of Stage IV. She also had seen others in her life go through breast cancer (other Stages) and reach a cure, further creating difficulty in her ability to understand her situation:

“I was diagnosed with stage 1 in 2007 and I knew quite a few people who had breast cancer including my mom so I just felt, okay I am the one out of eight I will deal with stage one and then I will move on with my life and I will be finished, you know I went through all of the process. I had the lump removed, I had chemo and radiation, took the pill, Aremadex and I thought that was it. I really did. I really didn’t even know what stage 4 meant. I went on with my life and then in 2010 thanksgiving weekend I finished my first marathon and two days later I went to get the result of a tiny little lump and then where they were spreading across my sternum. I went to get the diagnosis two days after. So I

was like YEAH I finished my first marathon, I feel great and I went in two days later and she was like you have metastatic breast cancer. Um, and I didn't know what that meant."

"I mean my mom was stage one and she has been cancer free for 12 years and mother in law has had it twice and she is cancer free. So, no one could understand stage four."

Having a curable diagnosis of breast cancer and having others around her become cancer free left her feeling confused and alone when she was diagnosed with Stage IV. Having been cured, feeling healthy and then receiving this incurable diagnosis was shocking. Her past experience with a curable cancer did not leave her with anything to compare Stage IV to. When the cancer was not curable, she did not know how to proceed.

Participant 3 also had a past experience in taking care of her father with Alzheimer's. This difficult experience taught her ways to look at her own Stage IV breast cancer:

"An experience that happened to me was in 2007 when I was diagnosed with this the first time. I was also taking care of my dad who had Alzheimer's and um, it was really, a teaching experience, taking care of my dad who was living by himself but I would go see him a few nights a week and dealing with the breast cancer...my dad moved in with me and it was just a violent situation and it was heartbreaking. So, I had to put him in a nursing home and my dad was very strong physically and he could break out of a room. Mentally he was completely gone. He was on no medicine though. But, when he turned violent it was dangerous. But, anyway to make a long story short. I felt out of control and he was on an overdose of drugs. It was horrific and I was devastated. Devastated that I could not control that situation. I felt like he gave up and he passed away. That was the most difficult time until I came onto stage four breast cancers. But, what I realized, I couldn't be in control of the situation. But, my mom said you did all you could and the best you could. I went to counseling for that and I felt like that's how I am going to handle this breast cancer stage four. There are things I can't control obviously but I am going to do the best I can."

Having this past experience with her father gave her the wisdom to focus on the things that she could control and not those things that she had no power over. This past experience with a

terminal illness was utilized in how she viewed her own cancer and how she will continue to live with her diagnosis.

Participant 3 also had experienced her brother-in-law's death from brain cancer. This experience led her to thoughts of her own mortality and how she may be seen when she is closer to the end of life:

“My brother in law at 46 died of brain cancer and he had two young children and I will never forget his wife telling me that as he was dying they were saying don't go daddy. I thought, I mean, I remember it was very difficult for him, he was sick. I don't want to go through all that and I don't want my family to. That was what I was thinking of, you know down the road, I mean should I think about ending it?”

Experiencing the death of a family member due to cancer gave her information on how to prepare herself and her family for her inevitable death. Additionally, she was able to see what could happen if she did not prepare herself and her family for her inevitable mortality.

Participant 4. Participant 4 is a 47 year old, Caucasian women living in Sherman, Connecticut. She is a single woman with few family connections. She has never been married and does not have any children. She has no previous breast cancer diagnosis, but has been living with Stage IV for 11 years. She is currently employed part time as a dog walker and has some graduate school experience. Participant 4 previously held a position as a free-lance photographer and artist, but is not able to continue that work due to physical limitations and financial struggles. She does not have a spiritual affiliation.

Although Participant 4 has not had a previous cancer diagnosis personally, she has had past experiences with cancer and death in her family of origin which has informed her decisions regarding her own cancer diagnosis.

“My mother died of cancer when I was twenty four. My step sister died of cancer in 2000. Those two experiences informed me somewhat. I have had my own ideas about if it ever happened to me. What I may or may not do about it and seeing a lot of people and what decisions and I have done a lot of volunteer work over the last few years with patients and have lost a lot of people. Being more clarified about what I will and won’t do.”

Having close personal experiences with family members who have died of cancer, and experience with volunteer work has helped to inform this participant about the decisions that she would make regarding her own cancer experience.

“Having gone through it with the family already. Having lost friends already. You know the makeup of my own personality and realizing that life is short. Bad things happen sometimes and that’s the way it is. I have had exposure to it and that probably freaked me out a little bit that I watched the process. You know how horrible it gets toward the end. I try not to think about that and it’s not something completely new. I didn’t have the kind of life; you know I have seen people who have always had a life that was really stable and planned out, then when something like this pops up it throws some people. But, I didn’t have that life anyway. I think I am a lot more use to change and instability. So I could deal with it a little bit easier.”

Participant 4 saw how bad cancer can be at the end of life and this created fear in her, but also a reality of the inevitability of her situation. She reflects on the instability that illness has had on her past and regards this as something that has prepared her for the instability of her Stage IV diagnosis. She reports having an easier time adapting to the changes in her life from her breast cancer, due to the fact that she has had a great deal of past instability from others who have had cancer.

Participant 5. Participant 5 is a 55 year old, Caucasian woman. She is single, with no children, living in Seattle, Washington. She had one previous diagnosis of breast cancer in 2008, Stage IIIC. She has lived with her current diagnosis for 1.5 years. All of her closest family and her best friend/romantic partner had previously passed away. She holds a Bachelor’s degree, but was currently unemployed. She previously worked as a secretary at the University of

Washington. Participant 5 labeled herself as Buddhist but describes herself as more spiritual and not practicing any specific practices of Buddhism.

Having experienced so much loss and death in her past has left her with a lack of familial support and a gratitude for the friend and community support that she has:

“In my case, my father died in 1999. My mother and brother died in 2004. They were all my immediate family so they all died between the first, and second time [I was diagnosed with breast cancer], well there was the love of my life, and also my best friend, and he unfortunately had a heart attack and died. Some other things happened so I haven’t had any immediate support from family because they don’t exist. In some ways it would be really nice to have a partner, I treasured my support from my friends and my community.”

The past experiences with death in her family, in combination with her past experience with breast cancer, gave her a sense of gratitude, despite her current severe diagnosis. Although still young at 55, these past experiences gave her a perspective where instead of being angry at her situation, she has knowledge that there are much worse situations to be in.

“I am a lot more, humbled, to be here, to be alive. Looking around here, comparing myself to so many situations. I do, some people say, I feel incredibly grateful. Getting this diagnosis, I am not a twenty nine year old mother of two kids. It’s still there are a lot of things I want to and need to accomplish before I die. I still think there are things I can do. Mostly on my own. Better my health, better my life systems. I still don’t have, certainly could do a lot better embracing my mortality and there are times, especially now, I feel a lot of social isolation because of what I have been through and in this last month in terms of meds and pain, um, you know, I could still be, I would really like a vacation from all of this, I can still be really overwhelmed. But I have a better grip on it than the first time around. I guess, maybe people become a little bit better about, not the best phrase, but learning to expect the unexpected.”

Participant 5 expresses feelings of isolation from the losses in her life, but is able to take her past and use the knowledge she has gained about life to help her manage her current life situation.

Participant 6. Participant 6 is a 50 year old, Caucasian women living in Chesapeake, Virginia. She is married and a mother of three children in their twenties. She has had three reoccurrences of breast cancer over a period of 12 years, leading to her final diagnosis of Stage IV. She has lived with Stage IV for 13 years. This lengthy experience with breast cancer has given this participant an extremely unique perspective on her Stage IV diagnosis. Breast cancer has been a part of her and her family's lives for 15 years.

"I was diagnosed in 1998 and I have had three occurrences. It has been tough and it seems like it always comes at the same time, in the same month, which this month I was actually diagnosed on St. Patrick's Day at 1:10 in the afternoon. I still remember what I was wearing, where I was sitting and what I was eating at the time. It has been 15 years this year. I don't know. I do think that it probably made me a better person. I think sometimes life just happens really, really quickly and I think that you take things for granted and I don't really do that anymore."

Participant 6 has learned to not take things for granted and has experienced how fast life can go by. Experiencing so many reoccurrences, she seemed to have a level of acceptance that breast cancer was always going to be in her life, even prior to the Stage IV diagnosis.

Participant 6 previously shared the cancer experience with her husband who had throat cancer during one of her previous bouts with breast cancer. This led to a bond and support from her husband, as they were able to go through cancer together.

"I just feel like I need to take care of myself and whatever it takes to do, that's what I'm going to do. My husband is right there with me. My husband is also a cancer survivor as well. My husband had throat cancer and he was a nonsmoker. When I was going through one of my treatments, my husband was going through surgery and that was a humdinger. We both prevailed. Both of us together."

The past experiences of breast cancer and having the support of her husband who also journeyed with cancer gave this participant the knowledge of how unexpected life can be and taught her to focus on the moments that she has and not take life for granted.

Participant 7. Participant 7 is a 59 year old, Caucasian woman living in Atlanta, GA. She is single, divorced and has one adult son. She had no previous breast cancer diagnosis and has been living with Stage IV for 4.5 years. Participant 7 holds an Associate's degree and was the manager of several storage facilities, but has recently been forced to retire due to her illness. She states that she has no spiritual or religious affiliation.

Participant 7 has had a powerful past experience with her brother who was involved in a terrible accident three years prior:

“My oldest brother he was in a motorcycle accident about three years ago, right before I was diagnosed and he is paralyzed from the waist down, so he, in the beginning I was as I said, I was not as positive as I am now and he would have no part of it. This guy boats, he just went on a 2,000 mile boating trip, he is going to Belize for the winter, now he lives in Canada so I don't live with him on a daily basis. We talk a lot. Talk about the power of positive attitude, so I feed a lot off of him. Now I do keep him up on my health, but I know that he has his dark days too. I try to stay as positive as I can and it's not like work, he is so positive and you know the guy has to get into his wheelchair from bed...”

Having her brother's experience to look at seemed to give her a sense of positivity that carries through to her own cancer. Not only is she reminded to stay positive for him, but she is also reminded of how resilient he is despite his handicap. This gives Participant 7 the unique experience of having someone to talk to when she is feeling down regarding her own chronic diagnosis. Remembering that she could be in a worse situation (getting into a wheelchair from bed) gives her a positive lens to look through when examining her own situation.

Participant 7 also had a mother who passed away of liver cancer. This experience added to a greater fear when she received her Stage IV diagnosis:

“...my mom passed away in 2007 and I was diagnosed in 2009. So my mother passed away of liver cancer and it was a very quick death... Her death, she didn't seem like she had a lot of pain. It was so progressed when she found out and it was a very quick death... I had the scans and so then right away I found out about that it had traveled to my liver and he said this is not your mother's liver cancer. I was just numb. Because when he said liver, oh my God, my mother just died of liver cancer and it was horrible.”

Having experienced the quick death of her mother and how fast liver cancer killed her gave her fear in the beginning about how long that she had left, particularly when she was told that the cancer was in her liver. However, she soon found out that her cancer was very different than her mother's and she was going to live with her cancer for a long period of time.

Participant 8. Participant 8 is the youngest of the participants at 46. She is an Italian/Japanese woman, living in Costa Mesa, California. She has a husband and three younger daughters ranging from the age of 16-21. She has had one other diagnosis of Stage IIB/IIIC breast cancer in 2007. She was again diagnosed with Stage IV in 2010 and has been living with it for 3.5 years. She has a high school diploma and was currently employed part time as a lunch worker. She did express that she would soon be moved to a sit down position in the cafeteria as she is having a hard time being on her feet all day. She labels herself as Catholic and is strong in her faith. She reports having a strong faith all her life, even when it was tested. Participant 8 had has a miscarriage in 2005 and linked this boost of estrogen to her first diagnosis of cancer. She became very depressed but leaned on her faith for her salvation.

Participant 8 had previous experiences of a miscarriage and being previously diagnosed with an earlier stage of breast cancer. These incidents gave her a sense of how she needed to view her Stage IV cancer:

“I don’t feel like I’m strong anymore. I realize that if you got cancer, you would do the same thing I’m doing because you have no choice but to do it. So I am not really any stronger than anybody else. I am not more optimistic than anybody else. I am just one of the lucky ones that my treatment is working well and I can function.”

She feels as if this is just the hurdle that she faces and she must live with it. There is a sense of acceptance of the circumstance that she presents based on her past medical challenges.

Due to Participant 8’s life stage, her young age, and her young children, her focus on her life drastically changed once she received her Stage IV diagnosis:

“I started taking a medical terminology class thinking I would have this second career, because after I was cured, which I don’t even believe in that word anymore. When my cancer came back, I had to drop the class, I mean I couldn’t even focus and then of course I was devastated and then at the same time, I threw away hope of having a second career because I figured that by the time my learning was done, it would be time to die. Plus I didn’t want to take time away from my children at school and doing homework, if I was just going to be dying. I wanted to be with them.”

She needed to shift her view of her cancer from wanting to accomplish things for herself before her cancer kills her, to wanting to make sure she did not miss being there for her children as they continued to grow.

Participant 9. Participant 9 is a 69 year old, Caucasian woman, living in Tuscaloosa, Alabama. She has a husband and two adult children. She has had one previous breast cancer diagnosis but did not specify stage and has been living with her Stage IV diagnosis for 3 years. She had some post graduate education and was employed part time as a teacher. She labeled her

spiritual affiliation as Episcopalian and was a very privately religious person doing most of her prayer on her own, although she would attend church.

Participant 9 had no previous experience with severe illness in her immediate family nor her family of origin. She reports that it was a very different experience for her to be the sick person:

“I did not grow up in a home with a sick parent, so this was different being the sick person; I have not been around a lot of really sick people.”

Participant 9 describes how her age and life stage contribute to how she views her Stage IV breast cancer:

“Of course at my age, people are dropping dead all around me, you know even younger people who are supposedly in good shape, runners, falling off their bicycles and dying in the road, from heart attacks and things. I think my age has something to do with my outlook. If I were 40, I’d probably be frantic every day and every time I had a hangnail I would think it was some new cancer, but you know I don’t want my life to end right now, you know I’m enjoying my life, but I’ve had a great life and I’ve got to have my grandchildren living here and be a part of them. I’d love to see them graduate, go to college, get married, and have babies. I may or may not. That is not going to keep me from having a good day today. The cold rain is affecting my outlook worse than the cancer, and I am sick of this weather.”

She is able to look at all that she has experienced with her children and grandchildren and be satisfied with her life. This has the ability to help her to not allow having Stage IV breast cancer to control her outlook on her own life.

Participant 10. Participant 10 is a 50 year old, Caucasian woman living in Alpharetta, Georgia. She had never been married and had no children. However, at the time of the interview she was living with her two nieces (19 and 17 years old) who she considered her immediate family. Participant 10 had no previous diagnosis of breast cancer and had been living with a Stage IV diagnosis for 3 years. She had some college education and was currently unemployed,

previously in advertising sales. Participant 10 did not label herself as associated with any specific religion but did hold very strong Christian beliefs and spoke of God often in her interview.

This woman had had a close personal experience with taking care of someone with a terminal illness. She had experience as her mother's primary caretaker through her illness and passing from Acute Myeloid Leukemia (AML):

"My mom died in 1995 from AML and I was for the most part her primary caretaker. So that definitely watching her, taking care of her, being with her in treatment, has been one of the things that influenced me. Just watching her no matter what, no matter how sick she was, going through bone marrow transplants, there are so many crazy treatments, she really fought the disease hard. She always, always, fought."

Not only was this woman able to see an example of strength, she learned a great deal about how to handle doctors and information:

"...my mom always made it very clear to doctors...we knew our responsibilities, I knew my responsibilities, me or my aunt if she was there, our responsibility was to ask questions of the doctors when they were around, because she was at a teaching hospital a lot and even if we didn't have questions that she could think of, we had to make them up, because her belief was, the doctor needed to know that beyond a shadow of a doubt, she had control of her care. She wanted their opinion and she got their opinion, but she was in charge and they weren't. I think that has been really significant part for me...I want her opinion [my doctor] and I value her opinion, but in the end it's my life and my decision. I don't think doctors are used to that, I really don't. I think they're used to coming in and telling you what they think you should do and everybody just kind of rolls over and says of course."

Learning through her mother's experience led to an attitude of empowerment about her own care and how it is handled. Additionally, seeing her mother so sick and going through so many treatments prepared her for her own future of treatments and the inevitability of her own illness taking hold.

Each individual participant has a different background of experience, family, and life stage. These individual characteristics play a role in the overall lens that these women examine their Stage IV breast cancer with. It is important to gain an understanding of these details in order to truly capture the lived experiences of this phenomenon, but also to be able to so clearly see the overarching themes that do arise despite individual circumstances.

Cognitive Appraisal

There are two aspects to the cognitive appraisal of having a severe illness, primary and secondary. Primary cognitive appraisal is the reaction to the diagnosis and first conceptualization of the illness. Secondary cognitive appraisal refers to the evaluation of the illness and how the person manages the demands of the illness (Samson & Siam, 2008). In the current study participants described primary cognitive appraisal through the examination of reactions to their Stage IV diagnosis and secondary cognitive appraisal with whether or not they have come to terms and accepted the Stage IV illness in their lives.

Reacting to the diagnosis. The reaction to receiving a Stage IV breast cancer diagnosis was very powerful for all participants. There were a range of emotional experiences including, shock and numbness. Women initially were in shock, feeling numb and were confused about what this diagnosis meant for their lives:

“She said I am so sorry to tell you what you have. Its metastatic breast cancer. I was in shock. I did not know what that meant I just know I had cancer. I will never forget, the nurse would not make eye contact with me.... I was in shock and was already at the oncologist the next day and that was a whirl wind of a week of just knowing I had cancer. I still did not at that point know what stage four meant. He just said you lit up like a Christmas tree. I said this sucks and he said yes it does. I started on chemo but again you are going to be dealing with this the rest of your life. I went on but I was just numb.” P. 3

Participant 3 describes the experience of hearing her diagnosis and how she felt numb from it. She explains how her first week was spent going to doctors and moving forward, but at the same time just trying to wrap her head around the fact that she had cancer. In her experience there was also a sense of understanding the magnitude of her diagnosis based on the reactions of the medical staff (nurse and doctor).

Participant 5 also describes this common feeling of shock regarding how she was making sense of this in combination with everything else that was going on in her life:

“Well I went in shock for about a day it was June 15th [the day she received the metastatic diagnosis]. It was a little harder; in fact it was two days before my fifty fifth birthday. So that was hard. I was one of the persons, rationally or not, I was one of the people who was like oh that’s never going to happen to me. In May 2012 I was just starting to get my energy back from all the things I had been through.” P. 5

This woman describes a common reaction to the diagnosis in the context of a person’s life. Each of these women had plans and previous views of their lives and when given this diagnosis, the rest of their lives changed. The importance of the Stage IV aspect of the diagnosis is the permanence of the disease. There is no room for these women to think that there will be sometime in the future when they will be rid of this breast cancer and where they could assume their life as it was prior to diagnosis. The change that these women must conceptualize is a complete and permanent life change.

Participant 8 highlights the differences between having a diagnosis of a curable stage of breast cancer and having incurable Stage IV:

“When you’re in an early stage and I was diagnosed as a 2B/3A (see Appendix A) so that’s not super early, but it’s not a 4. You are kind of built up by everybody as a strong courageous woman who is going to beat it. You start to feel like that. Where first of all everybody gives you positivity because they

don't want you to be scared. Which we need at that time. So you really do, when I see new women, I tell them the same thing, you will see how strong you are when you're done, you always assume you're going to be done, you'll see how much you can handle and see what strength you have and you see how important life is. Everything becomes special. Like the old cliché, the roses smell prettier and the sun shines brighter. All of that happens. The sun rises beautiful. My kids, babies first giggle. When I was diagnosed the second time, I thought I'm dying now, that's the difference. That's where you lose hope. You throw away your dreams and you think that you're dying that minute even though you know that you're not going to die that minute. I tell people, that's the first thing I say, you're not dying today. It took a while for me to feel like I wasn't just waiting to die." P. 8

With a diagnosis of Stage IV participants commonly described this idea of thinking that they will die soon and that this will kill them very quickly. This is a common misconception of this disease by those diagnosed and by the common public. Personally, prior to conducting interviews, I assumed that these women were not going to have had this disease for long before it would take their lives. This is not the case and women live many years with this diagnosis. Due to this, the primary cognitive appraisal includes an understanding that you are not waiting to die each minute, but that you still have many years of life, life that now includes living with and continually treating Stage IV breast cancer.

Accepting diagnosis. At the time of the interviews the participants of the current study were in the middle of life with Stage IV breast cancer, having now lived years with their disease. Secondary cognitive appraisal for this sample consisted of coming to terms with their diagnosis and accepting their disease. All participants reported a certain level of acceptance, some accepted it completely and others were still on their journey.

Participant 4 describes being totally accepting of her diagnosis but specifies what that means for her:

“Yes, I have [accepted my diagnosis]. I did pretty early. That’s largely my personality. Um, I am capable of accepting things that I don’t like and realizing that I can’t do much about them. So what are you going to do? So, I have had a little easier time accepting it than some people I have seen. That’s not to say that I am happy about it or totally okay about it because I am not.” P. 4

Accepting the diagnosis, for all participants, did not mean that they were content or satisfied with it, but acceptance was more an understanding of their situation and what they needed to do to negotiate the challenges it presented. Participant 1 elaborates on this acceptance:

“Well, I am a firm believer in you deal with what comes to you in the best manner that you can and I am disappointed, of course, ...because when cancer gets into the bone, I know that is going to spread and it is spreading, but I can sit around moan and groan and play Devil’s advocate or whatever, or I can do what they tell me to do and try to do it the very best and knowing that this is something I will have. I will have it as long as I live. I will be taking treatments as long as I live.” P. 1

Some of the other participants were not as confident in their acceptance and described different levels of acceptance:

“Yes and no. Yes, because it’s there, it’s reality. I don’t know how to describe this, but this is a hard one for me... At the same time, there is this weird hesitation and I don’t really know how to deal with that.” P. 10

Participant 10 explains that there is still hesitation even though she understands the reality of her situation. Participant 9 also describes how the fact that she feels physically good at the moment makes it harder to have a strong sense of acceptance:

“Well yes, I know I have cancer and I know that I’m not going to be cured and I know it will kill me one of these days, I just don’t know when, but I feel great so I guess right now, I’m in some sort of denial, because there is nothing flashing in my face saying you’re on the way out.” P. 9

Not feeling the physical effects of the cancer has caused a sense of denial for Participant 9. For many of the participants there seemed to be an overall sense of accepting the reality of the

situation but some levels of hesitation or denial when the cancer and/or treatments were not slowing them down physically.

Reality of diagnosis. There is another theme that participants spent a great of time describing as an important part of the cognitive appraisal of Stage IV breast cancer. The reality of how different having Stage IV breast cancer was from having other, curable, forms of breast cancer was a prominent focus within each participants' narrative. Living in a culture where breast cancer awareness is prevalent in everyday life, at the grocery store, NFL football games, commercials on television, etc., where awareness is centered on reaching a cure or being a survivor, creates a unique experience for these women.

First, many women described how they viewed the seriousness of their diagnosis and the incurable nature of their disease:

"I'm really intelligent enough to know that it's crazy, like Stage IV breast cancer, oh okay, shit!" P. 10

"You know when you have stage four. Uh oh, I feel an ache. Is it in the bones? I am going for an MRI tomorrow; I told her you know I have a headache... Of course yes, I question everything." P. 3

Many participants spoke directly of the difference that they felt between Stage IV and other curable stages of breast cancer.

"A lot of people don't understand stage IV cancer. I think in general and I used to think this too, I have the good cancer because it can just be cut off, that's an exact quote that I have said and I think the whole world thinks like that. I think the whole public thinks breast cancer just gets cured." P. 8

Participant 8 spoke personally about how she thought all breast cancer was curable and how she feels that the public in general views breast cancer in this way. Participant 7 had two powerful

examples of experiences she had directly with friends and family and their inability to understand why she was still sick:

“Yesterday at golf somebody said, is everything okay now? I said, no I’m stage IV metastatic, not curable. She just had a look like she didn’t have a clue. People like that, you want to almost say, yes everything’s fine because to me it is ignorance, but it’s not her fault.” P. 7

“My brother and his girlfriend and I were at dinner one night and I had a scarf on, but it was just because I like to wear scarves, and a lady came up to the table, a complete stranger at a restaurant, she said hello sister, are you a survivor? I said well kind of. She went, blah, blah and left. So my brother’s girlfriend said, you were weird, what was that all about? I said, it’s difficult to answer a question like that, because I’m still struggling with it. She said, what are you talking about?! I thought you had your lumpectomy and your radiation and your chemo. Here it is my brother’s girlfriend. So that was like, is it my brother that’s clueless? All of my family is in Canada. They don’t get it, even my own family. Because here’s a situation where she wanted to know why I was uncomfortable about that lady, and I said because I don’t know what to say, am I a survivor? Some people feel like you are a survivor from the day you are diagnosed. Well that’s not how I feel. When you see the cancer walks and all the pink things, you know, some people have stage 0 and they are out there. There is a lot of fluff out there. You don’t know that until you’re in the bubble.” P. 7

These two examples speak loudly to the specific nature of the disease. Many participants felt it difficult to explain their situation to “outsiders”. As Participant 7 put it, being in “the bubble”. She also carried with her a quote from a friend of hers with Stage IV breast cancer. The quote is in regards to how women with Stage IV seem themselves among women with other stages of breast cancer:

“My friend in the support group says, “we’re the turd in the big pink punch bowl”...I thought man ain’t that the truth.” P. 7

Participant 4 even reported the experience of having been asked to leave breast cancer support groups due to the severity of her illness:

“In 2003 when I was diagnosed there was breast cancer support groups and I would go there but, I would be the only stage four in there and I was actually asked to leave a number of groups because I scared them. They didn’t want to face that. Which I get it, it was a different set of concerns, there concerns were reconstruction. What do you do when you’re done with treatment, I just could not help it. Well, I am never going to be done with treatment and I am thinking about dying in my thirties, it was a different set of issues.” P.4

These types of experiences show that not only do the women in this sample feel that they do not belong with other, curable forms of breast cancer, but they communicate that they are receiving this message from both women who do have curable breast cancer and the general public (even friends and family). These participants are not creating their own “bubble” themselves, but are being separated and sometimes cast out due to the stage of their cancer.

Participants 9 and 10 reported an interesting realization of the fact that their breast cancer was incurable. The reality of the situation was difficult, but also gave them a certain sense of comfort when compared to other stages of breast cancer:

“From the first diagnosis, I think I lived more in fear of the cancer coming back before it did than I have since the second diagnosis, because now it’s back and they are dealing with it. I have more fear of the unknown than I have of facing a bad situation, but kind of knowing what I’m going into. I don’t like just being totally in the dark about things.” P. 9

Participant 9 was able to compare having a curable stage of cancer and the fear of it coming back with having an incurable stage of breast cancer and knowing that you can spend your time treating it. Participant 10 reports a similar feeling and how she prefers to simply treat her cancer:

“I look at so many of my friends, like I have three or four friends that have gone through this, they went through it, they had their surgery, they had their chemo, some of them had radiation, done, cross it off the list, no problems. In some ways I think that’s harder, because for probably 50% of them, it’s going to come back and so I don’t think I would want to live in that. I think that could be tricky to like know that, and so for me I kind of know. People have asked me, even doctors, oh, okay so it’s in remission, and I’m like no, not really. They look at you like you’re being dramatic, but I’m not.” P. 10

The theme of reality clearly shows the differences that are abundant between Stage IV and other stages of breast cancer. Each woman spoke of this reality and of the difference that they felt in how their cancer was something that would forever be a part of their lives and never something that they could be cured of or survive from.

Adaptive Tasks

Adaptive Tasks are the resources utilized and the components of how a person functions within their disease (Samson & Siam, 2008). These tasks include physical, psychological, social, spiritual, and vocational. Within these tasks the participants described the themes that arose for them and how these added to their experience of Stage IV breast cancer.

Physical. The physicality of this disease is undeniable. These women struggled with cancer in their breasts, lymph nodes, bones, liver, and brain. It was made abundantly clear, by the current sample of women, how physical struggles and the deterioration of one's own body influenced the experience of Stage IV breast cancer. There are two themes that fall under the physical category, treatment side effects and fear of future body deterioration.

Treatment side effects.

“One of the first times I went to the support group, this girl is like, “ah if the cancer doesn't kill you the treatment will”.” P. 5

The reality that the treatment side effects can be worse than the cancer was clear throughout each narrative. Even the participants who were physically doing well and treatment was working, had many stories to share about how past treatments took a harsh toll on their bodies. All participants discussed the numerous treatments that they took. Pills, injections, chemotherapy, radiation therapy, experimental drugs trials, and the like, were a substantial part

of living with Stage IV breast cancer. Each treatment was paired with a multitude of side effects and each treatment would affect individuals in different ways depending on their body.

“Sometimes you just don’t feel like you have control of your body from top to bottom.” P. 7

In some instances, treatments would be working and successful in slowing the progression of the cancer, but it would be breaking down their bodies:

“Once treatment started working, my bones were bad and I was told not to walk for a longtime and that put a damper on things. It did heal over time and eventually, a few years into it, I resumed as close to a normal life as I could.” P. 4

Participant 1 describes a lack of overall physical ability due to side effects from her treatments:

“The one thing was I was very active physically. I went to a work out three mornings a week and my friend and I walked like a mile and a quarter every day it wasn’t raining. We were doing all of these things and I had to stop all of that. That was not easy, because I know I am losing muscle mass and I don’t have a lot of stamina. I have to rest a lot.” P. 1

This woman also had to give in to taking pain medication, which is something she was trying to avoid:

“I am in I guess a bit of pain, I don’t pay a lot of attention to pain, but I have lot of pain in my shoulders and my neck, I am wearing a collar to try to relieve some of that and then the hip down the left leg. I am dealing with a good bit of pain and I am taking pain pills and that is something that I didn’t want to do, but I just can’t make it without them.” P. 1

It is interesting to see how in the beginning of the statement she describes a “bit” of pain and ends the statement with a “good bit” of pain. Women described a variety of physical ailments, including pain, sores, neuropathy, fatigue, hair loss, breaking bones, inability to walk, vaginal dryness, and low sex drive. The side effects to treatment seemed to create an overall difficulty in

the ability to live life and function on a daily basis. This deterioration of the body from treatments took away from the quality of these women's lives.

Speaking specifically to the differences of having a Stage IV breast cancer diagnosis when compared to curable stages of breast cancer, there is no end to treatments. These women were fully aware that the treatments that they were taking, the ones that may have been slowing the progression of the cancer, but were breaking down different physical and therefore active parts of their lives, would go on for as long as they lived. Each women described how their life was a process of moving from one treatment to another with the inevitability that you will run out of treatment options one day. Participant 7 spoke of this with emotion:

"I know I have a lump here and a lump there and things like that. One day we were talking about, once you have a scan and they know that the treatment you're on is not working, it's inevitable you're going to have this conversation. There are lots of chemotherapy programs, but ultimately you're going to run out and my doctor has said more than once, you know we're going to have this conversation one day. Of course, then you start crying." P.7

This woman was speaking of the conversation that she was going to have in the future about when to stop trying to fight the progression, when there are no more treatments to try and when it is time to allow the cancer to kill her. This is a startling fact for women with Stage IV breast cancer, that is, if they live to this point.

Future body deterioration. Despite the multitude of side effects that the participants discussed, at the time of the interview, many of the women were doing quite well physically. For example, Participant 3 was working on running a marathon with her daughters, Participant 7 was playing golf and traveling, and Participant 9 was not in need of physical support and was taking care of daily functions on her own. Towards the end of the interviews, half of the women spoke directly to the fear of how their bodies may deteriorate in the future. A striking reality that

women with Stage IV breast cancer face is the fact that their bodies will continue to deteriorate as they utilize one treatment after another. There will be a day where the options for treatments runs low and their bodies will be taken over by cancer. As the cancer spreads, it will gradually compromise more of their physical abilities. This is a guarantee with this incurable disease. This fear directly influenced these women's experience. Participant 3 gave an emotional answer when asked about the future of her body:

"That my life has not changed as far as doing my everyday thing, I am still doing my everyday thing. That's the reason why [my life quality is high]. It's because nothing has changed. Really I can do things faster because I have no hair to wash.

Researcher: But, if you get to a point where you can't do everything that you can do now, how will you keep your quality of life alive?

I don't know. I have thought about that. I don't know. I think that's going to be very difficult for me to deal with. I don't know." P. 3

When asked to rate her quality of life (0-10), Participant 2 gave her quality of life rating with a time frame:

"My quality of life at stage 4 is maybe 8 because there is a little bit of pain and side effects. Now I am not saying it will be 8 next year if you call me back or next month..." P. 2

Participant 8 expressed her fear with a vivid description of what her physical and mental state may be in the future:

"It's easy for me to say I've come to terms with it [cancer], because I feel really good right now. When it comes back again and when the medicines start to not help it, and when I know that I'm really dying and when I'm throwing up and my stomach doesn't feel good, and my kids are watching me suffer, and I think oh my gosh I really didn't do those 18 things I needed to do and now I'm dying and now I can't work, that my answer might be different." P. 8

At the point of the interviews, each woman described or alluded to the future and how quality of life may be impacted by the bodily deterioration from cancer and treatments down the road. The overall physical abilities that many of these women still maintained may have led to the higher ratings of quality of life.

Surprisingly, it was not the idea of death or mortality that created the most negativity in the physical lives of the participants, but it was the more unpredictable and unexpected future of how their bodies would feel. This in combination with the current and past physical responses to treatments created a difficult picture of the physical struggles that women with Stage IV breast cancer faced. The many different treatments that they endure and how these will continue the rest of their days is one of the most difficult differences between having Stage IV and another stage of breast cancer.

Psychological. The psychological adaptive task refers to how someone maintains control in their life and the emotional needs that they have to address. The women in the current study had three themes that were identified to help in the description of their psychology --mortality, a need for connection, and a need for education.

Mortality. Mortality was a powerful theme. Although, it is assumed, that all women who received a diagnosis of breast cancer, despite the stage categorization, examine their mortality or have thoughts regarding their own death, there is a strong difference within this population. Women with a Stage IV diagnosis, will die from their disease, but the timeline is a great unknown. The length of time that this sample had lived with their diagnosis was unanticipated by the researcher. These women were living multiple years with this diagnosis, and on average were doing quite well physically. This extended period of life after diagnosis, brought with it, an

extended amount of time to plan, dwell, and process mortality. Participants spoke candidly regarding this unique situation:

“So it’s very weird, basically you face your end of life issues way before the end of your life, so that even affects how you make decisions from now on. That’s a thing that is unique.” P. 8

“Yeah, it’s [thought of death] there first thing in the morning when I wake up. It’s there. That’s just the way it is.” P. 3

“So some people will ask me doesn’t that scare you, aren’t you nervous, and I’m like we’re all going to die sometime, right, we’re all going to have something to battle in our lives. I happen to have a more, keener awareness of it.” P. 10

These three participants were all describing the heightened awareness of their death and how it was present in their life.

Participants also spoke of how they were spending time making plans and preparing for their death:

“Holidays are bittersweet. I’m lucky I’m here for it, yet I know that one day I won’t be. The difference between me and you is that you know you’ll die someday, and I know I’m dying, it’s just a matter of how long it takes to get me. So it’s never really far from my mind. I am trying to live, but I am trying to plan my death.” P.8

“I need to do a whole lot more prep work regarding my mortality. There are a lot of things that I seriously need to take care and things that I seriously want to do and realizing the importance of working on, what I would consider, the best health possible.” P. 5

One interesting aspect of the elongated mortality of this sample was that it gave them time to prepare and gave them time to conceptualize how they were going to view their inevitable death.

Participant 1 describes how she responds to her mortality:

“...cancer can’t kill love and it can’t kill friends and it can’t kill, just a whole list of things cancer cannot do. It is very true. If you can live with that, then you can pretty well make it as far as your outlook is concerned.” P. 1

In her description, Participant 1 expresses that although there is a reality in mortality and that the cancer will be what kills her, that there are still many things that Stage IV cancer cannot kill such as love and relationship. This extended period of mortality almost forced these women to accept that this is a part of who they are, and they can either choose to live *in* their mortality or to live *with* their mortality and to use it to shift their perspective on life.

Participant 8 expressed the extent to which mortality and the length of time spent treating an incurable disease had on her family:

“My youngest one came up to me a year or so ago and said, “you know mom, will you be here when I graduate high school?” I said, absolutely, because I’m doing good. She goes, “well will you be here when I graduate college?”, and I said yeah, probably. She goes, “well what about when I get married?” Well that depends on how long you take to get married, but I said, I might be sicker by then because I’m preparing her. So she goes, “what about when I have my kids?” I said I don’t know, but just so you know, if not, I’ll be in heaven and I’ll be seeing you more than ever. That’s sad that I have to answer questions like that, where the average person doesn’t. It’s sad my kids have to worry about them. Life is precious.” P. 8

The last statement, “Life is precious,” truly captures how Participant 8 has to shift her view within her mortality. She describes a heartfelt conversation about death with her daughter and how her mortality is so unpredictable in regards to timeline. This unknown is not different from anyone, no one knows exactly when they will die, however, for women with Stage IV, they are given a more limited time frame and the prescription of what will kill them. This leaves these women with a perplexing situation to make sense of their inevitable mortality for themselves and for their families, particularly those with younger children, such as Participant 8. Additionally, the above quotation shows how the mortality within the relationship between her and her

daughter changes the relationship and leaves Participant 8 with the process of slowly detaching from her daughter's life. She is preparing her daughter for the fact that she may not physically be there at significant milestones in her life.

Living with the diagnosis of Stage IV breast cancer is a unique experience, particularly in regards to mortality. The women in this sample were placed in a situation where they needed to accept their unpredictable mortality timeline and utilize that in shifting how they will chose to live each day.

Need for connection. One of the commonly described aspects of how women in the sample dealt with their psychology was in regards to connecting with others. Each woman described the importance of making a connection with other women with a Stage IV diagnosis. Participant 8 describes the women with Stage IV that she has spoken with who feel so isolated and who does not have a strong connection to others:

“I just think it’s sad that the ones that are dying, some of these women lose their husbands, their husbands are tired of dealing with it. They lose their homes. They lose everything because they lose their jobs and then they lose their insurance, then they pay their \$900 COBRA bill till that runs out. Then by that time, they’ve lost their home and then they have nothing. Who cares about them? Somebody has got to. They don’t ever get to be done and get cured. I just hate that they feel so left out and so alone and God please somebody pay attention to me I’m dying from this cancer that you think you are doing so much for! My heart breaks for them and that will be me some day. Someday my heart will break for me too.” P. 8

Participant 8 gives an emotional description of the struggles of this disease and the isolation that can be felt. The need for connection between the participants and other women with a Stage IV diagnosis was prevalent. Unfortunately, few of the participants within this study utilized support groups or psychosocial resources. There was only one support group for metastatic breast cancer discussed that two of the participants frequented. The women who did not utilize supportive

resources reported not having access (location and travel difficulties), not knowing if any existed or not considering them.

Participant 3 describes her personal feeling of isolation, particularly in the beginning of her Stage IV experience:

“I was like, I don’t understand, I can’t find a support group. I don’t want to go through breast cancer, I don’t want to go to the other breast cancers, I am sorry they are not going to be dealing with what I am dealing with. I feel like mine is totally different when it’s not curable. Let’s be real. Um, I couldn’t find anyone I knew. I had friend who had stage 1, stage 2, stage 3 but no one is even in my group. I called the hospital and asked for a support group and they said no. So at MD Anderson I said to the woman and she said well, we did have one and they just died... I am still looking for a connection and I had a friend who was stage three and I was almost like... how close are you to stage four? I felt so alone that I did not have any resources.” P. 3

The last two statements show the desperation that she felt in the beginning and how she was reaching out to anyone who may understand her disease on a personal level. Participant 8, one of the two in a support group, continues this dialogue by describing the need for more support groups:

“If there are 30 support groups for breast cancer, why aren’t there at least three for metastatic cancer? Why doesn’t every hospital have one day a month just for the stage IV’s, even if only two people show up. Maybe it’s not financially feasible if you only have 2-3 people so you don’t want to waste your time, but guess what, somebody needs to waste their time because we have no one to talk to.” P. 8

The reality of the situation is that there are a limited number of supportive resources for this population. There is a need for more specialized support group resources that are specific to Stage IV breast cancer. It is important to clarify that the participants varied on their willingness to attend or desire to have a support group, but all women discussed the need to talk to others in their situation. Participants reported a need for more solidarity and knowledge of others going

through the same ordeal. Having other women to talk to about the unique experience of this disease is an important need for these women.

Several of the participants utilized internet resources and blogs specific to women with metastatic breast cancer. These were primarily used to gain information on treatments and side effects. Unfortunately, internet resources can be more impersonal. While these psychoeducational resources are beneficial and several participants had turned to these resources, participants also spoke about how the internet and its abundant resources did not meet needs for connection with others in similar circumstances. Participants did not report utilizing these internet base resources to discuss issues such as emotional struggles, and psychological reactions.

In addition to connection with each other, participants also spoke in terms of wanted to feel connected to medical staff. The need for doctors and nurses to be able to connect to their emotions was described by several participants. Participant 3 recalls an experience where human connection was not given when she received her diagnosis and this memory has remained with her for years:

I will never forget, the nurse would not make eye contact with me. That bothered me and it still bothers me today. P.3

For this participant, the need to be able to look at another's eye when she was going through such an emotional time was needed and not given. Human connection is something that the participants reported as a need. Participants describe a need for doctors, nurses and staff to have a greater understanding for the emotional demands of living with Stage IV breast cancer and to remember that as they deliver the medical facts regarding their cancer.

Need for education. The final need that was described by all participants was a need for more information in order to navigate their disease. The abundance of information that the participants reported having to learn regarding treatments, side effects, medical terminology to understand results, insurance information, hospital bills, and the like, was staggering. All participants expressed a need for clarity in information given, a way to access information in one place, and resources to help them keep up with all of the information necessary to successfully live with Stage IV breast cancer. Many of the women spent a significant amount of their time researching and trying to learn and understand everything that was going on with their bodies:

“I spend on the average, I spend 1-2 hours a day [researching on the internet]. I mean sometimes it is looking at forum sites of other women and discussions of the side effects- a cream for neuropathy or things they have found to help.” P. 2

“You know when I meet with the support group. Everyone is on different treatments and things I have never heard of and it’s like I didn’t know that was available and it’s overwhelming with the clinical trials. You don’t know enough about all that. It’s a learning curve. It’s been on the job training here. I told you when I went to my first oncologist. I was like, I can’t answer this, and I can’t answer that. So, she was like take this book home and read up on this.” P. 3

A reality of this disease is that it is very different for each individual woman. Among other things there is a great dependence on where the cancer has spread. Commonly among this sample it had spread to the lymph nodes, liver and bones, but it has the ability to spread to any organ in the body. This leaves the women with the need to learn about different organs, systems of the body, and how treatments affect each part of the body. When asked about needs, Participant 8 replied:

“Knowledgeable social workers. I have not really found many who know more than the average person through doing research. So, when I go to them and say here is my situation. They come up with the same old stuff that I have gone

through and can't do or didn't work for whatever reason. They just don't know anything else and I have to figure it out on my own anyway." P. 4

She was trying to search for someone who could help give some direction in the sea of all of the information she was trying to take in. Based on the narratives of this sample, these types of organized resources are limited. Participants 8 and 7 discussed how they looked to books for resources. They report that there are books out there but that the information is not always helpful or that they are not always available when they are needed:

"There was a book, I forget her name, she wrote a book, things that I wish I'd known about stage IV metastatic, yada, yada. It wasn't specific, this is what you need to know. Hers was all esoteric. You know, we had this charity event. I want to know am I going to get diarrhea, get constipated, those are the real issues...your body just shuts down and that's what happens. That's the real issue. Those are the things that I searched for." P. 7

"When my cancer came back the second time, there was possibly a book on the internet that you could order and it took two weeks. That doesn't help. I think it is getting a little bit better, but you need to hear about your story and what people go through when they are like you. All of that was missing. You're desperate for that kind of stuff. I got a book called 101 questions about metastatic breast cancer, but I swear it took a year to find it. By that time, it had been a year, I needed that my first week. I don't understand why there is not a way for them to let people know that stuff is out there." P. 8

The participants in this sample shared thirst for information, direction and help in navigation. This was a powerful need among all women. Despite the individual circumstances, from the woman with amazing health insurance and a close family to the single woman who had to rely on friends and was battling pharmaceutical companies, all participants spoke to a need for more information and clarity in how to obtain that information.

Social. The social adaptive task refers to the family, friend and community relationships that people utilize to navigate their disease and gain support. The description of social support emerged throughout each individual narrative. This was a common theme across all cases.

Supportive relationships discussed included family (of choice and of origin), friendships, neighbors, and communities (i.e. church groups, exercise clubs, blog websites). The women described how relational support was essential in living with Stage IV breast cancer and this support helped them in many ways including personal growth, relieving of psychological distress, and provided them with the knowledge that they were loved and cared for.

“I think it’s a really key thing [social support] and can be a game changer. If you have it or don’t. Whether it’s from family or society as a whole.” P. 4

Family Support. Family of origin and family of choice were both represented in each participant’s story. Women discussed two concepts regarding familial relationships; support from family in the form of tangible supportive behaviors and giving and receiving love. Support, both in actions and in love, were a key aspects in increasing the quality of life of the participants

Family supported these women in many ways. First, were the tangible supports such as bringing food, calling to check in, going with them to doctor appointments, and taking up household duties. These types of supports were extremely meaningful to the women.

“My daughter-in-law who is the sweetest, kindest, most sensitive person, she is quietly the most supportive person in my life. She doesn’t talk about it, she shows up with little container of pimento cheese from Zoe’s, and then she always knows when I’m getting ready to go to an MRI or a PET scan and they’ll just be a text message or an e-mail that says, you’re in my prayers. I’ll be thinking of you tomorrow. It’s just the little things.” P.9

“My husband has gotten to be a better husband now than he was before cancer because he is more conscious of really taking care of me, as opposed to the normal situation where the wife does everything because that’s what wives do. So he has gotten good at, he makes dinner for me on the days that I have my chemo which is a very gentle chemo, but it makes me sleep so he knows I am not doing anything that day. He is not upset if the house gets messy, all that kind of stuff. It has been actually very good for our marriage. Not that it was like bad before, just that he is more conscious of me. He worries about me and thinking about me and you know what I mean. Everything we do is more together.” P. 8

The tangible acts of support such as bringing over food or sending a text message left women with the knowledge that someone is thinking about them. Being in the thoughts of another person in their lives was meaningful. Additional forms of love expression came through in the details:

“He has been very supportive, but I try not to lean on him too much. He always comes to the big doctor appointments and things like that. He is a very, very positive person too. My very first day of chemo, we sat next to this lady and her husband and she was I guess in remission and it came back and she was like (moaning) and he said move now, I don’t want you sitting next to her.” P.7

Participant 7’s son was very observant of his mother’s comfort and aware of how she may have compared herself to that woman. In this moment her son was showing her care and thoughtfulness. Participant 3 describes a tangible show of family support in the form of her husband agreeing to move closer to her children:

“When I was diagnosed I lived outside of Orlando for thirty years and my daughter moved here (Atlanta) and my oldest just had a grandbaby. We had always wanted to move and right after that diagnosis we said we are going. So my husband said I don’t know how we are going to do this but we did. So we moved here this past June and we are near the baby.” P. 3

Uprooting his life, her husband knew the importance of supporting Participant 3 in her want to be close to her grandchild. Although it was difficult for them, he supported her by helping her make this a possibility.

Family support was also seen in the form of giving and expressing love. Participants who had strong family connections discussed communicating love and feeling love from their family members.

“We have these illnesses, but a very, very close family and so there are six of us left and of course, in-laws of those who have deceased, so you can see that I am just wrapped up with people who love me.” P. 1

Participant 1 describes feeling “wrapped up” in love. Families that have always been close and loving, continue to show this love particularly when a member had a Stage IV diagnosis. However, for some families, the illness had transformed familial relationship, creating more discussions of love and the act of giving love more openly. Participant 8 describes this relationship transformation in terms of a deepening and growth in intimacy:

“We talk about the things that are important. How much I love you and how much you love me. How much I want this to be. What makes me happy, what makes me sad? I know my husband better than I ever did and my kids better than I ever did because we talk about those things that people normally hide. It’s the same way with brother, sister or friends. We’re not afraid to be like around people and love right out in public.” P. 8

Participant 8 describes a processes of personal growth in the love and intimacy that she shows toward her family and that she expects her family to show her. This is a clear example of how family relationships can grow rapidly with the diagnosis of Stage IV breast cancer.

Participants who had families all spoke of the love and support that they felt. Having these familial relationships added to the quality of life for these women. The majority of the women (8/10) described a great deal of family support and those who did not have it, relied heavily on other supportive systems.

Family difficulties. Participants within the current study described an additional area within family relationships that was of importance. Families, in varying detail, all had difficult reactions to the diagnosis of their loved one. Some dealt with it better than others and all had their own way of handling the illness:

“Well my husband still is having a very hard time with this. He is an introvert and he keeps things in. He has a very hard time talking about it, like when we talk, like right now. We, the girls and I, we are at the point where we crack jokes about it. Like are you pulling the cancer card again mom? That kind of

stuff. He doesn't find that stuff funny. So he keeps a lot of it inside. You know I talk, talk, talk, and he listen but you know. Like yesterday, I said I have a back ache and he said that's just the way you are sitting and my other daughter was like no dad it's not the way she is sitting. You know what I mean? But that's the way he is dealing with it. I come very open and we talk about it. Every time we get the results he comes and my daughters and my mom come when I have chemo. But, he comes for the results and he has very little to say. He only speaks when he has something to say and he did say how much he likes this doctor here. So, um, I wish he would express more. But that's him, he keeps it inside. He has talked about it to my daughters crying." P. 3

Participant 3 captures a common reaction, specifically with husbands. Several women described how their husbands were supportive tangibly, but were not expressive with their emotion and did not wish to have conversations regarding the mortality of their loved one. Participant 9 also describes this lack of connection between her husband and her illness:

"He compartmentalizes things. I think for a long time he dismissed it, he put it out of his head, it's not true. Because he would say things to me like on days I literally could hardly walk from the bedroom into the den and sit down on the sofa and think I just don't even have the strength to go to the kitchen and get a glass of water, he would say things like, I wonder why you feel so bad. And I would just look at him and think, because I have terminal cancer you dumbass." P. 9

Participant 9's husband showed signs of denial around his wife's disease. This created frustration with the participant. The communication between spouses regarding the illness were not all lacking in connection, but this was an aspect of the spousal relationship that came up several times.

There were also few instances where family member's negative reactions were of a destructive nature to the relationship:

"I was like, wait, so you stopped eating sugar and all that because of my diagnosis and she says yea. It really blew me away, I mean she radically changed her life. She stopped using deodorant, she won't buy deodorant for her daughters, she won't eat sugar, it eased up a little bit, but she cut out a lot

of processed foods in her diet, and will not have a mammogram... My sister and I rarely speak anymore.” P. 10

Participant 10’s description is very powerful and shows how deeply some family members are affected by Stage IV breast cancer. It creates fear for the individual with the illness, but can also create fear for the family. Her sister was terrified that she was now in danger of developing Stage IV breast cancer. The genetic component of breast cancer is real, but it is of interest how it changed how she viewed her whole life and how the relationship was damaged.

These examples of difficulty in familial relationships due to the illness were common and of varying degrees. Overall, however, the reactions of family members and their own processes surrounding Stage IV breast cancer need further attention.

Friends/Community. The women in the current study discussed in depth about the outpouring of community and friend support that they received at the time of their diagnosis and beyond. For these women, friendships and community were not distinguished and seen as one in the same in regards to support given. Those women in particular who were lacking in familial support were more dependent on the gracious support that they received from their friends and community:

“So I haven’t had any immediate support from family because they don’t exist. In some ways it would be really nice to have a partner. I treasure my support from my friends and my community.” P. 5

All of the participants described some form of support from friends or community. Some had more support than others. There were several women who had such overwhelming support that they described an intense feeling of love, care and gratitude:

“Yes, I would say when people find out that you have cancer, the outpour of love is just overwhelming. I still have every single card that people sent me

when I was first diagnosed. I have one of those little mailboxes and it is completely filled from all the way to the back to front and all the way up to the top. The meals that people brought me and how caring they were to take my children when I had my treatment. I would just say that I never knew that I was that well liked or loved until, you know you have friends and you do things with your friends, but you just never know how people really feel about you, you know what I mean? You know, you have acquaintances come out of the woodwork and they just do nice things for you and feed your family and send you nice cards and just thoughtful things. It really makes you feel loved and touched. It still happens now. I had my last surgery was coming up on two or three years ago, I fractured my femur and I had cancer in my femur and I had to have a rod put in my hip. I didn't tell anyone at work until the day before I had my surgery and it was just amazing how much they cared about me and visited me, the people that I exercise with and the gift cards, the dinners, it's just the outpour is just phenomenal." P. 6

Participant 6 describes an overwhelming outpouring of care from friends and community members. She was very touched by this and even shared how it showed her how people truly saw her and cared for her, something she did not know prior to her Stage IV breast cancer diagnosis.

"This group of people [Sunday school class] and my family of course they just rally around me constantly and the whole thing, but these people they bring me food, they take me to the doctor when I can't go on my own, they call me. I have cards that I actually I guess they would stack two to three feet high that people . . . it's rarely a day even, and this has been going on for several years now, it's rarely a day that I don't get a card or a call or food, or something from one of them and all of them without exception offer to drive me where I need to go, come sit with me if I need someone, this kind of thing. So, I am just totally surrounded by the most wonderful people considered on the face of the earth frankly." P. 1

The amount of support shown to these women is inspiring, but even more so is the length of time that this support is shown. The current sample had been living with Stage IV breast cancer for an average length of 6 years. This is a big difference with women who are not Stage IV. The level of support is long term and sustained in so many of these cases. Support was consistent for many of these women throughout that time frame. However, this was not always the case.

The uniqueness of Stage IV breast cancer is shown with the length of time that these women fight their disease. For Participant 10 the support was great but she states “initially” what the support is like:

“With this disease, initially, almost like to the point, not to the point, I couldn’t even keep up with people. There were so many people who were like I’m thinking of you, I’m praying for you, you know just really like this onslaught literally of people who wanted to support me and love and encourage me. I think I felt so much love and care in all of that, it was absolutely incredible.”
P. 10

Later she described how after a period of time she would stop updating friends and they would lose sight of her illness and of showing support:

“...then I kind of got to the place where, ugh, I don’t even know, it just got to be, how do you even tell people, I don’t know. Once you stop updating it [friends regarding her illness], then I kind of lost sight of it [friend support]. P. 10

Participant 9 experienced friends who did not understand her acceptance of her disease:

“A couple of my friends’ reactions were a little startling when they were a little disappointed when I didn’t fall apart. I had one say, you’re not acting right. I said what do you mean by acting right? Well you’re acting like nothing’s wrong and I said well, there isn’t anything I can do about it.” P. 9

This friend’s reaction shows the lack of understanding that some people had in regards to living with Stage IV breast cancer. When you live for so many years with an illness that is slowly killing you, that is not a curable form of breast cancer, it is difficult to understand that the only option is to create a level of acceptance and continue with your life. This is particularly difficult for friends of women with Stage IV specifically, because breast cancer has such a connotation with survival and cure.

The magnitude of relational support that these participants received and the impact that it had left women feeling loved and cared for. This theme consistently appeared in all narratives and touched the lives of each woman in a positive way, regardless of the amount or type of support given. However, it was a fact that due to the longevity of struggle with this illness, friend and community support, in many cases, trailed off. If the women did not keep others updated or did not wish to, this form of support was subject to have less of an impact over time.

Spiritual. The spiritual adaptive task refers to how faith and spirituality is utilized to help conceptualize the illness (Samson & Siam, 2008). Faith for participants was seen through both, the lens of a specific religion and through more unspecified ideas of spirituality. Faith was used as a way to cope with the cancer diagnosis and/or as a way to have a sense of peace that everything would be O.K. Participant 2 took ownership of her diagnosis by not letting it become an evil negative aspect of her life:

“I have never talked to Satan before and never plan on it again. I know he goes after mother Theresa and Billy Graham, he would never bother with me. But, that first time I had the breast cancer diagnosis and came out from that and getting my PET scan back that it was in my lymph nodes and things. I told Satan this is my cancer not yours and you can’t touch it. It is only for the glory of god.” P. 2

This woman was not going to allow her cancer to become a negative aspect of her life and was going to take control and fight her cancer through her treatments. Framing her cancer diagnosis with her views of religion seemed to give her a sense of control in a situation where her cancer was spreading out of control in her body.

Participant 10 felt that she had been prepared for her diagnosis, by God. That she knew that there was going to be a challenge in her life and that this was it. This created a sense of calm for her:

“For me what was significant about them [PET scans] was every step of the way, I haven’t had fear. For me that’s just my faith. I feel like God even before I knew I had cancer, I knew that God was preparing my heart for something, He made it very, very clear. So on the day I was having my mammogram, I knew before the doctor even told me. I looked up at the mirror above the ceiling and I went, oh, I literally just felt in my heart that I knew that this is what God had been preparing me for and asked me to prepare my heart for.” P. 10

Through her faith and belief in God, Participant 10 was able to frame her Stage IV diagnosis in a way that fit into her life. Although she knew she would die from this disease and that it was incurable, she was able to see this as the challenge in her life that was given to her straight from God. She felt that God had prepared her for this and this gave her, again, a sense of control, similar to Participant 2.

Another aspect of Faith that was expressed frequently by participants were experiences that they had that led them to believe that a higher power was giving them a sense of peace. This led to a relief in fear for participants. These expressions of faith were seen through significant experiences that some women had early in their Stage IV experience:

“I have got to tell you this one thing. The last time I had a PET scan before this last one it was June and I was living with my mom, I was moving here. It was in the middle of June and I was living with her and I was going out for a run and the phone rang and they called me and they said well it’s been growing and it’s grown here and there. I got off the phone and I cried. I took off out the door. I went for a run and it was raining and I took off and started crying and I just couldn’t miss that run. I will never forget this guy passed me on a bicycle and he said, “I admire you” and I said, “you have no idea”. That was so cool. Just out of nowhere. I thought was that just meant to be?” P.3

Participant 3 spoke of this man as someone who was put into her life, just at the right moment and giving her a comment of strength right when she needed it. In that moment she was feeling very overwhelmed and fearful of the fact that her cancer was growing. In that moment of pure emotional distress she was given a message of strength. Participant 6 had a similar experience

where she felt that God was speaking to her in a moment where she needed to be reassured that she was going to be ok:

In my original diagnosis, I had six positive lymph nodes and I looked up in the sky and I think this was during my treatments, I looked up in the sky and I said God, please give me a sign that I am going to be okay. Please, please just give me any sign whatsoever that I am going to be okay. And you're not going to believe this, but I found six pennies while I was walking just here and there all scattered, and they were all heads up. And I was like, oh my gosh, and there I just said thank you. You know what I mean, it was like oh my gosh, I am going to be okay because that was to me it was like a true connection to the big guy upstairs. Yeah, you're going to be okay, you're going to have to work, but it's going to be okay. It's really funny, because to this day, whenever I see a penny and I look down and it's heads up, I'm like, there you go big guy. You're looking at me aren't ya? It's probably all for naught, but it was my way of thinking that I'm going to be okay. Even when I do laundry and there is money in the washing machine and I look and it's heads up or I have money in my pockets, and I look at that and it's heads up, oh my gosh. That was like a defining moment for me. P. 6

Being "okay" was not defined as the cancer being cured or that she would survive the Stage IV cancer, but that she would be able to continue to function and continue to have hope in her life. Participant 6 describes this communication with God as a way for her to keep hope in her life. Additionally she describes feeling a sense of security that God is looking out for her, even when she is suffering with her cancer. Seeing pennies, heads up, means that she still has hope to live for. Although this was one of the 3 women who did not label themselves with a specific religion or spirituality, she found ways that worked for her to connect with her higher power.

Having a feeling that God was looking down on them and that he/she was acknowledging their situation was a significant experience in how these women lived with their diagnosis.

"I can pray and praying helps. When I'm really upset, I cry and I cry to God and I talk to God all the time, I'm never like, if I'm super stressed out, I just go God I just can't take this and it's almost like, I guess I would have to say, it's almost like it's therapeutic, because I always have someone to talk to even if I'm alone. And I don't feel stupid doing it." P. 8

Participant 8 describes how having God to talk to in the hard times, means she is never alone. For many women their religion or spirituality gave them a sense of continuous support that they could always go to and always count on.

Every woman spoke of faith, spirituality and religion as a support. Never did a participant respond that this was not a support for them. Even Participant 4, who states she does not have a religious label and even during her interview labels herself as agnostic, found her own way for her beliefs to give her a sense of peace:

“I put my faith and sense of spirituality in physics and the universe and the complexity of it. The fact that the laws of physics says energy never dies and it just transforms and this sense of whenever I am going to die I will return back to whatever it was I came from and that does stay with me and one of the reasons I like being out in nature and like staying close to that... That does give me peace. It helps.” P. 4

Spirituality was a continuous source of support and was an aspect of life that helped to create control, sense of peace and calm and a sense of hope in the lives of these women. This theme illustrates how quality of life was drastically increase.

Vocational. The vocational adaptive task refers to occupational work (Samson & Siam, 2008). For this sample working, not being able to work, being forced to retire and health insurance were all a significant part of this component. Financial struggle, due to lack of work and/or struggles with health insurance, was one of the most common causes of stress and difficulty as reported by participants:

“Sometimes the huge thing is financial. That’s a whole other world because of the financial. People don’t know how to pay the bills and pay the doctors and that kind of thing.” P. 2

“Well it’s hard. It’s hard. And something that us longer termers have is the financial devastation of it all. It’s one of the largest challenges that have

cropped up over the last couple of years. Everything changes, it's an adjustment. You have to constantly adjust. I am in one of those phases right now. I could write a book on it." P. 4

Financial struggles were described throughout the narratives as most difficult because the illness had such a long term impact, leading women to have to stop working and leaving them in a constant battle with insurance companies over the multitude of treatments and medication they were utilizing.

Leaving work. Ceasing work represented several different scenarios for these women, including early retirement, having to change from their career to a less physical job, only being able to work part time or having to directly quit. Only 2 of the 10 participants reported working a full-time job. In each scenario the women discussed how the change in work status impacted their lives:

"In work, that was frustrating. I was an artist and photographer and I couldn't keep doing that." P. 4

Participant 4 later describes how she tried to restart her career, but to no avail:

"Then at some point trying to revive my career which got seriously sidetracked. Then I started to work around the fifth year, I guess [with Stage IV]. That went well for a while and then around the seventh year realizing that I was going to go completely broke and try to address how I was going to get back and that was a huge challenge and in some ways bigger than the cancer." P.4

This woman describes how over several years her career would begin and end. Participant 4 had her own career as a photographer and artist and struggled to keep business going, eventually having to quit due to financial struggle. The work that she loved, she was not able to do. This was due to a combination of physical restrictions and lack of energy. After years of trying she had to give up on her career.

The physical deterioration results in many women having to change their jobs to something less physically straining.

“Now what they are doing, they are moving me to a position where I’ll be more deskling [sitting at a desk]. I’ll be the manager where I’ll be doing the money and accepting money from the kids and counting the money and there will be other people doing the heavy-duty work. That to me says that I have at least two more years that I can work instead of maybe not.” P. 8

Participant 8 described how she used to work in the kitchen as a lunch worker and how she loved her work and interacting with the kids. However, she was on her feet all day. Due to blisters from a treatment and the weakening of her tendons she is not able to stay on her feet and is taking pain medication every night to function. This leads her to think to the future, stating she feels she only may have 2 years of working left.

Participant 9 describes a combination of doctors’ appointments, biopsies and physical energy as the root of her having to quit her job:

“I had to quit that, because librarians do not sit at the desk all day long. You are on your feet and when I got diagnosed, I mean I had been subbing all the way through January and end of February and then I had this head scan that showed all these things, I never went back again, because from that day on, I was scheduled with doctors, biopsies, and then started chemotherapy and I just didn’t have the strength or the energy. That just went to a halt.” P. 9

Stage IV breast cancer can not only cause physical ailments that create difficulty in working a job, but also the demands of the doctors’ appointments, treatments, scans, biopsies, and therapies, that need to be completed and during business hours. This leaves very little time for women to work a full-time job, particularly if the job is not supportive in giving time off for these types of medical appointments.

A combination of physical strain and time spent treatment Stage IV breast cancer led many women to have to retire or quit their careers. For several of these women they took great pleasure in their work and considered this a joyous part of their lives. To have to give that up was something that took from these women's life quality. Several women who were still able to work part time were not doing what they loved to do and had to redefine their vocational part of their life to fit in with their Stage IV diagnosis.

Health insurance. Connected to the difficulties of not working or changes in jobs and abilities, is the second meaning unit, "Health Insurance". The women that participated in this study became emotional when talking about health insurance. The most common emotions expressed were anger and frustration. More than any other topic, the topic of insurance created fire in these women. Some participants had a more difficult time than others in dealing with the difficulties surrounding insurance. This was due to dual vs. single income homes, family vs. individual plans and working vs. unemployed or on disability. However, all women cited this as a source of burden and stress:

"So, you know you are already dealing with chemo, side effects, baldness, neuropathy, you're going to die. You have an incurable disease and I've got to deal with this [health insurance coverage]. So you know, thank goodness they make antidepressants." P. 7

Participant 4 described how insurance was directly impacting her ability to make more money and the frustration that came with that:

"I am on Medicaid now and I can't earn more than \$600 per month. So, I am forced into a box where I had to give up photography, I can't sell prints anymore because I am on Medicaid and every time I think about doing something, I think I can't do that because I am on Medicaid. I am stuck in a trap and it's extremely frustrating to me and I am struggling with that a lot." P. 4

Participant 2 could not help but feel personally attacked by insurance and pharmaceutical companies:

“What I have come to discover is, the enemy to me is big pharma and why. I mean it’s against me personally, it doesn’t want me healed.” P. 2

Later adding:

“So, do I feel like a victim? Yes, yes. But, I am so tiny. So the best I can do is fight with the information I have.” P.2

This group of participants, in particular, felt that they needed to help others that were in the same situations they were:

“Number one, I had to worry about insurance and that has been the biggest hurdle. Financially, every time you get a bill in the mail, it’s a lot of stress on the financial end. Some people have great insurance, some people have mediocre. Some people have none. I always felt blessed to have insurance and now I’m caught up in a predicament and so I want to be able to have a voice for that.” P. 7

Even going as far as committing illegal acts:

“There are people begging for it [an experimental drug treatment]. I know this is recorded and I will probably go to jail for it. But, I had some of that medication left in the back of the cabinet which I was talking about. One of the woman on the forums was begging for it because her insurance company was fighting it and it was helping her. So, I got her name and address and sent her my eight pills. Which she thanked me profusely. They hadn’t been open and she had an RX. She didn’t just read something in readers digest and think that would help me. But, you see that is something that is against the law.” P. 2

It is important to make the clear distinction that not all participant were in such strenuous predicaments with insurance, and not all participants felt as victimized as, for example, Participant 2. However, those women that were single, unemployed/retired, and or had a single income, seemed to experience a much more difficult battle with health insurance than others.

This subsample of women is an important group to highlight. Based on the narratives it is clear that this was a population of women that fell through the cracks in the system and were sometimes left feeling victimized.

The difficulties with health insurance is unique to Stage IV breast cancer for two reasons. First, battling health insurance will be just as much a part of these women's lives as the cancer itself. As long as they are treating their cancer and taking medication, health insurance will be a part of their life. Second, the multitude of differing treatments, medications and experimental treatments that these women utilize to slow the progression of their disease creates a unique level of difficulty when trying to get insurance coverage. Overwhelmingly, for all women in the sample, this was an aspect that took away from their life quality. All were affected even if to varying degrees.

Coping Skills

Samson and Siam (2008) describe "Coping Skills" as what comes from the adaptive tasks. It is how one copes that then determines a positive or negative outcome for someone suffering from an illness. For the current sample there is one clear theme that arose as how women cope with Stage IV breast cancer. Making meaning in their situation was essential in the coping process. Making meaning meant something different for each woman, but commonly relationships, faith and finding a purpose in life were utilized to create meaning.

Making meaning. The ability for participants to create a meaning out of their experience seemed to be the key aspect in having a high life quality. Understanding that there is meaning behind their lived experience was essential. All participants spoke of differing meanings in their lives that were linked to their cancer. Some meaning came in the form of having meaningful

relationships. For other participants it was having meaning in their faith. And still some would simply create purpose in their lives as a way to assign meaning.

Relationships. Participant 6 and Participant 8 created meaning in their lives through their relationships with their immediate families. Watching their children grow, being able to see significant life stages and being close with loved ones was extremely meaningful and added to their life quality:

“Watching my children grow up is the best. Watching two of my three children graduate from college. My baby still goes to college, as a matter of fact my middle one, the 23-year-old is getting her Masters and graduates in May. My son is getting married in August. My children and my husband are my biggest milestones and my attitude I think has a lot to do with it. I just refuse to give up.” P. 6

Having the experiences of watching her children grow, learn and develop and having a close relationship with her husband gave Participant 6 a reason to never give up on life. When asked what were the significant milestones in her cancer experience, this is how she answered, highlighting the familial relationships within her life. Participant 8 continued this meaning by describing the love she feels when she is close to her husband, her children and her dog.

“People say that there are blessings in tragedy and you wouldn’t think that there are, but there are. With all the things that are frightening and scary and fearful and upsetting and everything, I am closer to my husband, I am closer to my children, I am closer to my parents. I’m truly fortunate that I wake up every day, who can say that. I love my dog. I have a roof over my head, although it’s falling apart. I just love to see my kids smile. I love holding my kids hands. I love it when they come and talk to me and tell me about their day.” P. 8

The relationships in her life gave her meaning and reason to get up every morning.

Participant 5 found meaning by creating connections to people all around her. She utilized humor and valued getting to know people:

“I’m just remembering, there were times when I had my first complete mastectomy. I remember writing with a marker on my stomach using sort of a backwards mirror words, on my stomach I put, “my surgical team is the best”. Just to give them a chuckle. I mean this is just something, humor has been important for me in all kinds of ways. I mean I really-really like people and so when I get the chance, it’s really nice to get to just find out some more about these people.” P. 5

Having connections with people was meaningful to Participant 5. Even relationships that were not as close as a family member were meaningful and she found joy in connecting with other people, including the doctors and nurses that were a part of her life.

Faith. Meaning was also created through the use of participant’s faith. Commonly, participants would lean on their faith to make meaning of their own mortality and the reasoning as to why they were diagnosed with cancer. Participants utilized their faith to answer the questions surrounding, “why me?”:

“I don’t know why God lets things happen, however, I know I’m not alone and I know that Jesus suffered way more than I am and that his suffering did good. I’m Catholic so we believe that Jesus loves us so much, he lets us unite ourselves to him and so our suffering can help him do what he does with his suffering. We believe that because I am part of the body of Christ, if I’m suffering, I’m somehow helping to bring about salvation because Jesus is uniting my suffering with his, which brings about salvation. A lot of Christians don’t believe that, but as a Catholic I do, therefore, my suffering has some purpose so even if I don’t like it, it’s not quite as bad as I’m just suffering for no reason. I just trust God. If I die tomorrow, I trust God that it’s because it’s my time tomorrow. That helps a lot.” P. 8

Through her faith, Participant 8 felt that there was a deep meaning in her suffering. The idea that she suffered for a purpose was meaningful and her faith had the ability to give her this.

Participant 4 utilized a non-religious belief as an attempt to normalize the meaning of her experience and to remind herself to find quality in her life:

“I think you have one shot at it. We are alive for a limited amount of time. Some people get a couple of weeks and die as infants and some get to a

hundred years. I do not believe in an afterlife. I don't believe in heaven, I don't believe in hell after reading all that either. I never did. It's just like everything else it's a normal thing, everyone lives, and everyone dies. It's a normal thing."
P. 4

For several women, faith and spirituality was utilized to create meaning in their experiences of Stage IV breast cancer. These meanings added to the quality that they felt in their lives.

Life purpose. Creating meaning in life also presented through the lens of having a life purpose. Life purpose was described as helping others, contributing to society, and focusing on activity. Many of the participants created this type of meaning in their lives. Participant 3 discussed how her life purpose was remembering to be active, doing, as opposed to being stagnant:

"So, I am doing okay. I keep busy. You know and I am trying and I have job interview next week and the support group. They ask me do I really want to work and I am like yeah it keeps me busy you know. As long as I can." P. 3

"Now I try to get 25 hours out of the day even though there are only 24. I really do." P. 3

She continued by later describing how quality of life is related to her activities:

"Just being, everything quality of life is being, everything that I can get out of a day. My family, my friends, my activities, social life, job." P. 3

Participants 1 and 8 both spent time discussing how their life purpose was linked to service and helping others. Participant 8 had aspirations of starting an organization for women with metastatic breast cancer. She wanted to give back to those suffering and help to raise funding to increase the quality of life of other women:

"Then I started on this organization, foundation that I'm starting and I was hoping please let this happen fast enough so that I can help someone before I die. There was like I don't know when it happened, but one day I realized that I am planning something that is going to at least take years if not more years

and the fact that I was okay with working on something like that was kind of like the sign that I am not planning on dying anymore. So that really was kind of like almost like a bubble burst inside me that said wow, I'm not planning to die, I'm planning to live and I have hopes and dreams again. You really do you just kind of throw those away. So that for me is a really significant thing is the mental change from a dying cancer patient to a living cancer patient." P. 8

Having this organization as a purpose has literally redirected her focus, from death to life.

Additionally she describes the meaning behind accomplishing something of importance:

"Before I die, I'll do something important too. I guess you need to ask what's good about cancer. Is there anything good about it, because there is, but sometimes you've got to search for it and then you might be helping people." P. 8

For Participant 8, helping others was the "good" in cancer. It created meaning in her life and also meaning in her cancer experience. Participant 1 also discussed life purpose as how she creates meaning. She began by addressing how she could not physically help others around her anymore and how this was a loss for her:

"I guess probably what I needed or what I felt the loss was to not be contributing anything to society basically. That was one of the things that was always very important in my life to fill people's needs where I saw and I can't do that. I can pray for them, but to go to them, you know, I can't do that anymore." P. 1

Throughout the interview, this woman began to reflect on how she could still make meaning and how she could help contribute to society. She discussed how my interview led her to start to think outside of the box of ways that she could still help others. It was an amazing experience to see this develop throughout the interview:

"I have such an extended family and friends that I have not suffered from lack of attention I guess would be the way to say that, so that I really don't know, but this has opened up a cord of interest with me that not everybody has the attention that I have. That makes me responsible for seeing if there is anyone

who does need it and so it gives me a project. I am going to research that and see what is there. Like I said, I have such a wide circle of friends, acquaintances, family, neighbors that I am afraid I have just been sitting here letting them fill my life with wonderful things and enjoying instead of seeing what I could do for someone else. That's not my nature, but you certainly have called my attention to it." P. 1

Making Meaning was the most commonly discussed theme throughout the 10 interviews. This theme was predominantly related to positive aspects of life, feelings of love, feelings of faith, and feelings of purpose in their lives. Creating meaning literally gave the women the ability to continue to wake up each morning and face the day with something to look forward to. More than positive attitude, more than having support or having faith alone, it is the creation of meaning that led to greater life quality. Particularly for those participants who had less support or did not rely on their faith, meaning was the vehicle to an increased quality of life.

Outcome. Samson and Siam (2008) describe the outcome component of their model as either a positive or negative outcome for dealing with a severe illness. For the current population, outcome came in the form of quality of life. With all the aspects of the lived experience of Stage IV breast cancer, it was the women's ability to create quality in the life that they had that led to positivity. The theme of creating quality in life was a process more than a direct concept that was brought up by the participants. The researcher asked three direct questions to the participants regarding their quality of life. The first question inquired that participants describe their quality of life, second, to rate their quality of life on a scale from 0-10 and third was in regards to what they would need to create a greater quality of life. Many of the participants discussed life quality prior to these questions and after this line of questioning.

When asked how she would describe her quality of life, Participant 5 states:

“I think it’s good [my quality of life]. It could be a lot better and it could be a lot worse. Quality of life is meaning. I am so thankful I own my home, I can live independently but I am so lucky I have friends, I have community, I think for the most part I am getting really good Western care. I have things I have to do, I have things I’m looking forward to.” P. 5

Participant 5 eloquently described many aspects in her life including relationships, the care that she is given, activities, things to look forward to, and having a home as the things that increase her quality of life. She reports that it is through those things that she creates meaning in her life and that it is this meaning that adds to her life quality. This is directly in line with the Comprehensive Task Model outlined throughout the study.

All participants were asked to rate their quality of life. The ratings of life quality on a 0-10 scale (0 low and 10 high) were high, with an average rating of 7.5 (See Table 4.1). This points to an overall positive outcome among this sample in the experience of living with Stage IV breast cancer.

Table 4.1: Quality of Life Participant Rating (Scale 0-10)

Participant	Quality of Life Rating
1	5
2	8
3	8.5
4	5
5	6.5
6	10
7	8
8	6-7
9	8
10	10

Participant 10 had one of the highest self-reported ratings of quality of life. She describes that her illness challenges her and how she gains a sense of growth and movement from that:

“I would rate it a 10 and I guess the reason is that physically yes there are definitely some impacts, in this, but I feel like it’s growing me, it’s challenging me. For me that’s a quality of life, I’d rather be in that part, I’d rather be challenged and stretched than to be stagnant. In this, you cannot be stagnant, you can’t. So I guess I feel alive.” P. 10

For her, Stage IV breast cancer keeps her going and makes her feel alive. This is an interesting conceptualization of an illness that will undoubtedly lead to death. Participant 10 finds meaning in being active in her life and her disease keeps her active, as she states she “cannot be stagnant”.

Participant 6 also rates her quality of life as a 10 and relates her illness to being a challenge:

“I have an awesome quality of life. Because I allow myself to. Even though it is always in the back of my mind, I will not let it win. I cannot let it get in the way of what I want to do... A 10. An absolute 10.” P. 6

She eludes to fighting her illness and not letting it win and take over her life. By keeping her life quality high she is able to fight her cancer.

Some participants linked their rating of quality of life directly to a prior theme. For

Participants 1 and 2 this was their relationships:

“I guess we’ll say a 5... I think because of the circle of my friends and family, I would be on a 2 or 3 [without friends and family], it is wonderful to know that if I called on one of them, they would come immediately, you know, and the granddaughter being here, so I would say a 5.” P. 1

“So that’s my quality of life it’s not just physical, it’s social. So I would say 8.” P. 2

Although Participant 1 rated a lower quality of life, she describes that it is her relationships that give her a 5. Participant 2 defines her quality of life as directly linked to her social connections.

Overall, the life quality was higher than anticipated, due to the severity of their diagnosis.

There are participants, however, that stated their quality of life was not high. Specifically, Participant 1 and Participant 4 gave the lowest ratings of 5. These participants described the struggles that they have with specific themes that took away from their life quality:

“Maybe not so good [my quality of life]. It was good; reasonably good all things considered it was pretty good. The past year in particular I am starting to question it. I don’t think it’s all bad yet but the developments of the last year have definitely brought to the floor that I am getting into that place... Some of it’s physical and some are the finances... I would say an average of five [rating quality of her life]. Sometimes four sometimes six. But probably rate a five.”
P. 4

Participant 4 is clear in describing the two major themes that were common among all participants as themes that decreased life quality. The two themes that take away from having a high life quality are the Physical and Vocational struggles (i.e. treatment side effects, future body deterioration, leaving work and health insurance). Participant 1 also specifically describes physical struggles and future body deterioration as what leads her to give a rating of 5:

“I hadn’t thought of that, but I guess we’ll say a 5. I can still walk around, sometimes I have to use a walker or a cane, but I can still get around a little bit. I don’t always drive the car, but most days I can drive to where I need to go. I don’t know how long I’ll be able to do that, but right now I can.” P. 1

In examining the outcome through the lens of quality of life, the women within this sample utilized many adaptive tasks to cope with their illness by creating meaning in their lived experience of Stage IV breast cancer. This meaning that is created directly adds to quality of life of the sample. There are however, certain adaptive tasks that create a great deal of stress and struggle and directly take away from quality of life.

Understanding Stage IV Breast Cancer

Through the process of conducting, recording, reviewing and dissecting the 10 participant interviews, it has become abundantly clear that I, as the researcher, will never truly understand the experience of living with Stage IV breast cancer. As Participant 7 labeled it, you must be in “the bubble”. I am not in the bubble. However, throughout this experience I have gained knowledge that has led to an outcome that shows the experiences of 10 women and how they live each day striving for and achieving, a high quality of life.

Women with Stage IV breast cancer do create quality in their lives. Through the relationships that they form with family, friends and communities, these women experience love and care. Through the faith that these women hold onto when the illness rages on, peace, and calm are felt. Through staying active and helping others these women create purpose in their lives. It is a combination of relationships, faith and life purpose that lead women in coping with their illness. This coping is accomplished through the creation of meaning. Women with Stage IV breast cancer may experience some of the same meaning making that others with a terminal illness face. However, this population is unique in that they are living each day facing mortality and facing a cultural misunderstanding of that mortality. Thus, creating meaning faces greater challenge for this population.

The participants within this study struggle. From those with the highest rated quality of life, to those with the lowest, they struggle. Financial and physical stress interact and take away from life’s quality. Some women cannot work, others spend hours on the phone with their insurance company. All women suffer from physical ailments from the treatments that are battling their disease. These treatments fight a war with cancer but also a war with their bodies. Aches, pains, sores, fears of headache and normative bodily pain, are always on their minds. Fear

of the future. What the future will bring for their bodies and how their lives will change is a constant burden.

Women living with Stage IV breast cancer have needs. More than anything they need to be connected to each other and they need to be connected to information. No one can understand them unless you are one of them. These women have a need to connect to the resources that they have in each other. The participants also have a great need for guidance in the uphill battle of learning what this disease is all about. From specific side effects of the newest drug to ways to help your family cope, these women need education and information.

The simplistic explanation presented does not do these women justice. It does not capture the complexities of the illness, nor the strength that each of these women puts into each and every morning. However, this explanation does capture the difficulty of this disease, the uniqueness of this experience and the ways in which these women address some of the many struggles that they face.

CHAPTER 5: DISCUSSION

Summary of the Findings

The women within this sample provided a detailed description of their experiences with Stage IV breast cancer. Each experience was unique with personal characteristics influencing how each woman viewed her life with cancer. Age, past diagnosis with breast cancer, and previous experience with terminal illness of a friend or family member were the three most common themes that the women spoke of as having an influence on how they conceptualized their Stage IV breast cancer diagnosis. Although these women had diverse narratives, many similarities emerged. The most consistent theme was the reality of Stage IV breast cancer and the uniqueness of this disease. Throughout the process of conceptualizing, adapting, coping, and outcome (Samson & Siam, 2008), these women spoke of the difficulty of living with mortality, in a culture where breast cancer is seen as curable and where women with breast cancer are labeled as survivors. These women felt as if they were a population of outsiders where the general public was ignorant to their unique situation. They were not fighting to beat their cancer but fighting to slow the progression and create a quality life despite the disease that would eventually kill them. The creation of quality of life as an outcome for these women was developed through the utilization of adaptive tasks that led to the ability to cope. Coping with this disease occurred through the creation of meaning. Meaning was created through relationships, faith, and life purpose. Although a small sample, the quality of life ratings were high among the population and this was directly linked to each woman's ability to create meaning about her experience.

The findings clearly showed that the experience of Stage IV breast cancer was unique when compared with other stages of breast cancer. This uniqueness touched on all aspects of the experience, but was evident in the themes of reality and mortality. Reality was described as the unique experience of being a minority within the larger culture of women with breast cancer. The realistic concept that these women would not survive their cancer and that they would live the rest of their lives fighting their cancer, created a distinct perspective. The women in this study did not resonate with being a survivor of breast cancer, which is the focus of much of the breast cancer community's marketing and advocacy. This title of survivor is a culturally accepted definition of women who survived breast cancer and were cured of it. The women in this study were living with their cancer, but would never reach the title of survivor. Mortality was also a common theme. Each woman was fully aware of the unique experience of having a long term disease that was slowly killing their bodies. Some women described this as living with mortality. The women had many years to contemplate their death, project what their future may be, and prepare themselves and their families for the inevitable. However, this time also left room for some denial and pushing the thought aside. The knowledge that the cancer would continue to spread left these women with anxiety surrounding every PET scan and fear whenever a new symptom would arise. Understanding these unique themes is essential in understanding the experience of Stage IV breast cancer. These are the unique circumstances that these women dealt with on a daily basis.

There were many difficulties that these women expressed, linked to the unique nature of this disease. The participants' experience with the illness was difficult physically and psychologically. Physically, body deterioration (both currently and past from side effects and the fear of future deterioration) was either a current battle limiting their ability to work and enjoy life

activities, or a future battle that created fear of what would happen to their bodies in the future. Psychologically the women struggled first with the thoughts and emotions around mortality. This was a reality that these women woke up in the morning with and went to sleep every night thinking about. The knowledge that they had a disease that was slowly killing them and the only fight they could accept was one that would slow the progression of the cancer, created many difficult emotions. Women described feeling scared, shocked, and devastated, particularly around the time of their diagnosis. Psychologically these women also struggled with the stress of feeling isolated and a lack of education and information regarding their experiences. The women spoke of a need for connection to each other. Due to their unique circumstances, women spoke of wanting to be close to those who had their same diagnosis to share information, emotional connections and strategies. Some described the need for more specified support groups and others described a more broad need for any form of connection, despite the medium. The women within the current study also described a great amount of stress and frustration with all of the information they needed to gather and learn about their disease. For these women there was now, literally, a lifetime of education that they needed to obtain. This information was not easily found and the women described a need for a more organized source of information.

Linking Theory and Experience

The theoretical models including Samson and Siam's (2008) Comprehensive Task Model and Wright's (2003) Relational Understanding of Life and Death were combined to create theoretical tenets (see Table 1.2) which were utilized to understand the lived experiences of women with Stage IV breast cancer. These tenets were personal history/social context, cognitive appraisal, adaptive tasks, coping skills, outcomes, and relationship with life and death. Each of these tenets were utilized to inform the research questions and create the semi-structured

interviews. Through the process of data analysis, each of these were addressed, and combined, describe the lived experience of Stage IV breast cancer.

Personal history/social context. Samson and Siam (2008) describe this tenet as individual personal history and how it influences a person's ability to adapt to a stressful situation. In the context of the current study, age, past diagnosis of breast cancer and past experience with a friend or family member who had a terminal illness, were the most commonly discussed themes that influenced the ways in which these women adapted to their experience. The data supports this idea that individual characteristics influence the ways in which each woman adapts to her circumstance.

The specific characteristic of age has been previously cited as influencing how women adapt to breast cancer (Epping-Jordan, et al., 1999; Jones, Cheng, Jackman, Rodin, Walton, & Catton, 2010; Lindop & Cannon, 2001). The older women within the study were able to see their cancer through a lens of a full life. These women spoke in grateful ways regarding having been able to see their children grow and have children of their own. Younger women faced more difficulties with having to explain their cancer to their younger children and worrying about whether or not they would be around to see their grandchildren or to grow old with their partners. Age, specifically for Stage IV breast cancer, made a difference for these women whose mortality was an everyday reality for the rest of their lives. Women that were in the later stages of their lives had an easier time accepting this daily mortality, while younger women thought more about their young families or the goals that they had for their lives that they had to give up.

Women that had previously been diagnosed with breast cancer had mixed reactions to the Stage IV diagnosis. Some felt more prepared and others felt more security in the predictable

nature of Stage IV's incurability. These women had experienced being a survivor and beating breast cancer only to be devastated and shocked by a reoccurrence. Having the knowledge that this cancer was not going to be cured gave them a sense of security without holding a sense of false hope. Other women had a very hard time with the Stage IV diagnosis having had the expectation that their previous cancer was finally gone and that this difficult part of their life was completed. The women with previous diagnosed breast cancer had many mixed emotions with the Stage IV diagnosis. For many of the women, breast cancer was more easily accepted as a part of their lives since they had previously spent time with a lesser stage of breast cancer. All women with a previous diagnosis were influenced by their past experience. This led to either an easier acceptance of their disease or one that was more difficult to navigate. Some women felt a sense of preparation from their previous experience while others felt defeated that the cancer had grown worse and was terminal.

Women who had had a previous family member or friend with a terminal illness described a level of proficiency in medical and emotional knowledge. The women described their past experiences as learning opportunities and discussed how they learned emotionally how to handle illness, and how it influences individuals and families. Medically, many of the women were able to better navigate the process of communicating with doctors, gathering test results, and even knowing which doctors and hospitals to utilize. Both the women with a past breast cancer diagnosis and those with a past experience with terminal illness possessed an ability to problem solve, whether with medical decisions or decisions regarding how to communicate with family and friends. Having the ability to cope and problem solve has been linked to lower levels of distress, anxiety and depression in women with breast cancer (Epping-Jordan, et al.). The findings of this study support the tenet that personal characteristics influence how women

experience breast cancer and that they utilize these past experiences to adapt to current circumstances.

Cognitive appraisal. Cognitive appraisal refers to the process of conceptualizing the experience of illness (Samson & Siam, 2008). Primary cognitive appraisal and secondary cognitive appraisal are the processes of understanding how an illness will influence an individual's well-being and how to manage the demands of the illness. More specifically, Samson and Siam describe this as the process of reacting to and conceptualizing the illness, leading to the individual's ability to complete tasks to adapt to the situation. Previous literature has focused primarily on the first level primary cognitive appraisal and how women react to their diagnosis (Svensson, et al., 2009). The current study also examined the reaction to the diagnosis, but moves to the secondary cognitive appraisal and examines where the sample was in their process of acceptance of their illness. Reactions to the diagnosis varied among individuals, but all experienced initial feelings of shock and numbness. This reaction was linked to the reality of what Stage IV meant, that this was a disease that was slowly killing their bodies, and would eventually lead to their deaths. Several women had a difficult time understanding what that meant and/or how to wrap their heads around the concept of inevitable and unyielding mortality.

Most in the current sample had lived many years with their diagnosis and were at a place where acceptance of their disease could be assessed. All participants reported some acceptance and none were in complete denial. There were few women who were doing very well physically which they reported led to denial of the magnitude of their disease at that point in time. However, all women reported acceptance and specified that this did not mean they were happy about it or that they were content with having Stage IV breast cancer. Acceptance was defined as

knowing that their cancer was spreading and that they were treating the progression, but that it would eventually progress, leading to their death.

Adaptive tasks. Samson and Siam (2008) describe adaptive tasks as the specific actions taken to achieve healthy adaptation to a chronic illness. These tasks include physical, social, psychological, spiritual, and vocational. Previous literature specific to this population had only briefly described social tasks. It has been shown that women with metastatic breast cancer utilized community, spend time with pets, and communicate their thoughts and concerns with friends and family (Svensson, et al., 2009). The current study goes beyond finding what types of tasks women utilized, by identifying how these tenets of the theory are utilized in the experience of Stage IV breast cancer.

Physically, women in the sample had to overcome many difficulties. The side effects of treatments were debilitating and touched every system in their bodies. The fear of future body deterioration was also a constant thought that the women in the sample struggled with. These physical difficulties were a very real part of the experience of Stage IV breast cancer. However, women within the study were able to make it through treatments and find those that would lead to the least debilitating physical side effects. The women in the sample were physically doing quite well at the time of interview and spoke mainly of the process of treatments that they went through and the fear of how their bodies would fare in the future.

Socially, the women in this sample utilized support from community, friends, and family as a way to build meaningful and valued relationships in their lives. This led women in the sample to feelings of love, caring, and kindness. These relationships were essential for all women and those who lacked closeness to others were vocal in the negative impact on their

lives. Although having relationships was positive, there was a negative side that the women also endured. This was the process of disease acceptance that family and close friends were going through. The women in the current study described several examples of how their husbands, or children were having a hard time coping with their disease. The reality of the situation was that there were not many known resources for the sample to help guide them with the difficult aspects of some of their relationships. Overall, relationships were essential throughout the process but there are clear stressors involved among these relationships.

Psychologically, the women within the current study had several difficulties to overcome. First and by far the most salient was the psychological impact of mortality. The unique experience of living the rest of their lives with the knowledge and heightened awareness of their own mortality created an interesting situation where the women had the ability to process, plan and conceptualize their own death. These women had the ability to discuss their death with their families, but also had the downfall of having an unpredictable timeline for their death. Having to live life with the knowledge of disease that is killing your body, but never knowing exactly how long you have left to live, creates a strange sense of life. For the sample it created awareness of how precious life is and gratitude for what they had in their lives.

Additionally, the women in the sample spoke of their psychological needs; the need for connection to other women with Stage IV breast cancer and their need for help in gaining the information to navigate their illness. Connecting to others in the same, unique situation, was described as a way for the sample to process their experiences with their illness and to share in the difficulties of their disease. All women spoke of reaching out to others and the difficulty in finding other women with the same diagnosis. The other need that women spoke of regarding their psychology was the need for education regarding their disease, treatments, medications,

side effects, and the like. As has been described, the information that these women need to obtain is immense and the organization of this information is lacking. Having a way to obtain information and resources that could help them to gain understanding of their experience was a common need among the sample.

Spiritually, the women in the sample all spoke of how their beliefs helped them to create meaning and understanding in their lives. The women turned toward their faith and felt a sense of peace and calm knowing that their faith was strong and that they had strong beliefs in whatever events of life or death would be in their future. All women in the sample utilized spirituality as a support despite religious affiliation or agnostic beliefs. This adaptive task was utilized to help the participants make sense of their current situation, their mortality, and how they viewed their disease. Having a spiritual presence in their lives gave many of the women a sense that they would be “OK” as defined by being able to accept and adapt to their disease.

Vocationally, women described their current or previous employment and how this was influenced by their Stage IV breast cancer. The majority of the women in this study (8 out of 10) experienced a negative impact on their work abilities. This included being forced to retire, being forced to quit, having to change jobs, having to give up careers and having to work a less physically stressful role at their place of employment. This shift in work force created stress in the sample. The most stress was felt from those who had to leave careers and quit their jobs altogether. This left many women feeling disappointed that they could not achieve the vocational goals that they had set in their lives. In relation to this, another stressor that was common within the sample is the difficulty in navigating health insurance and managing medical expenses. Health insurance stress was greatest with women who had to leave their jobs and/or those women who were single with no children and no dual income. The frustration with insurance

coverage, particularly with the longevity of treatments, changing treatments and experimental treatments was unique to this stage of breast cancer. Although health insurance coverage is a common concern for many individuals with long term illness, these women commonly utilized experimental treatments and their treatment regimen was commonly changing as the cancer spread and as each year passed. The women who were not employed due to physical limitations had a great deal of burden financially with limited coverage. These vocational stressors were a common cause of decreases in the quality of life for this sample.

Coping skills. The Comprehensive Task Model describes coping skills as the means for which adaptive tasks are accomplished. The finding that making meaning, in the experience of Stage IV breast cancer, was the key component to coping and creating quality in life, supports previous research on meaning making with the terminally ill. Cancer patients who reported a high degree of meaning in their lives experienced significantly more enjoyment than those with a lesser level of meaning, despite physical pain and fatigue (Brady, Peterman, & Fitchett, 1999). The types of meaning that were found to be influential in increasing quality in life, relationships, faith, and purpose, are also supported by previous research. Frankl (1959), in “Man’s Search for Meaning,” describes three categories of meaning that are created in the face of a difficult life circumstance; creativity, experience of relationships/beauty, and attitudinal. Creativity is describes as being actively engaged in different activities, experience of relationships and beauty refers to sharing love with others and having appreciation for the beauty in things, and attitudinal refers to the attitude one holds about the illness and how they create purpose in that situation (Greenstein & Breitbart, 2000). The current study found that the women in this sample described these same categories of meaning. Meaning was illustrated through relationships and love, faith and how they utilized faith to make sense of their cancer and mortality and finding a life purpose

through activity and service. Frankl's category of creativity is very similar to the description of staying active and being of service to others. Relationships and beauty were also described, specifically, love and relationships gave many of the participants a greater sense of meaning in their lives. The category of attitude describes the way one views their illness and situation. Faith was utilized in this way to create meaning as some women used their beliefs to have a more purposeful view of their illness and their current situation. Meaning was the catalyst in the creation of quality of life for the women in the current sample.

Outcome. The major outcome for adapting to the disease of Stage IV breast cancer, in the current study, was creating optimal quality in life in the face of a grim diagnosis. Previous literature specific to this population, describes health related quality of life (Karamouzis, et al., 2007; Lidgren, et al., 2007; Weinfurt, et al., 2004). Health related quality of life specifically focuses on physical side effects. It has been shown that the multitude of physical symptoms that come from treatments decrease quality of life (Weinfurt, et al., 2004). The data from the current study does support previous research that body deterioration from side effects takes away from quality in life. Women in the current study, however, not only described the past and current physical ailments from treatments, but also fear of the future. Overall, the sample of 10 women were in relatively good physical condition and were able to function at a moderately high level (take care of daily chores, get to doctors' appointments, go out socially). Due to this, these women described another aspect of health related quality of life; fear of future body deterioration. Many of the women in the current sample directly expressed this fear and how their quality of life would change in the years to come as their physical symptoms began to worsen. This fearful anticipation of the future directly took from their quality of life.

Quality of life was increased through having meaning in life. Relationships, faith, and having a life purpose were utilized to create meaning in life. This coping strategy was directly linked to increases in life quality for the sample. All participants discussed how their quality was linked to meaning either through relationships, faith and/or creating a life purpose.

Relationship between life and death. The Relational Understanding of Life and Death (Wright, 2003) describes how men and women who were at the end of life create a relationship with the idea of life and death. Wright describes six different relationships that can occur (see Table 1.1), but also states that these are not limited and that simply a relationship does occur. Within the current study, life and death were categorized within the Stage IV specific characteristics of mortality and reality. Women within the sample described these two characteristics, not in terms of positive or negative, but more matter of fact and as part of their identity and their daily life. Many women discussed the feeling of living with mortality or as if they were fully aware that life was on a count down. The fact that these women were actively fighting a disease that was slowly killing their bodies became the basis for their narrative. Mortality was also accompanied by the reality of their disease. These women are a dying minority in a majority culture that focuses on survival and cure. These two factors play an important role in the relationship that is then created with life and death. The current study does support Wright's theory and a relationship does emerge, but it is more of an identity with self, than a relationship with an outside concept. In regards to the six, highlighted relationships, the women in the current study experienced a combination of them. Wright describes seizing the death, seizing the day, life and death transformed, and waiting for death. These relationships include the creation of new found interest in one's death, developing a new found meaning in life, defining dying as a journey and accepting that death is coming, respectively. Based on the

current study, the women experience all of these. The relationship that women with Stage IV breast cancer have with life and death is much more complex than one distinctly defined relationship, but is a combination of many ways to examine life and death. It is for this reason that the women in this study speak of life and death as more of an identity than a relationship. It is not something outside of themselves that they can turn away from or that they can ignore, it is a part of every moment in their lives.

Conceptual Model

Throughout the narratives, the concept of living a quality life was described. To better understand how women with Stage IV breast cancer create quality in their lives a conceptual model is presented (see Figure 5.1). The model addresses the research question and describes the factors that increase and decrease quality in life. Relationships, Life Purpose and Faith are the three factors that help to create meaning and give meaning to life for the women within the sample. Familial relationships and friend/community relationships helped many of the women to cope with their disease. This creation of meaning is then the key factor that adds to quality. Having strong relationships gave women a sense of love and caring giving their lives meaning. Life purpose was defined through being of service to others, contributing to society and being active. Women found ways to feel purposeful in their lives despite their illness and this gave them a sense that there was meaning to their life. Faith was the third way that women created meaning. Faith and spirituality gave women a way to make meaning of their illness and meaning of their mortality. It helped women to have some understanding that there was a reason for their suffering and other women a way to make sense out of their inevitable death. Through relationships, faith, and life purpose these women created meaning in their experience which was directly linked to the quality within their lives.

The participants described those aspects of life that were linked to increasing quality but also described the factors that took away from their quality. Financial struggles (vocational) and body deterioration (physical) are the two factors that take away from having quality in life. These two factors are connected in that the deterioration of the body plays a role in a woman's ability to work, keep her job, and the decisions around retirement/stopping work. The loss of work issue created additional stress around health insurance, particularly if they were not married with a single income. Additionally, the fear of future deterioration was a significant stressor and was commonly discussed as an aspect of the experience that drew from having a quality life.

Three additional themes are also represented in the model; personal characteristics, Stage IV specific characteristics, and needs. Personal characteristics influenced the entire model, and all themes within it. Past breast cancer diagnosis, experience with a terminal illness, and age/life stage played a role in all themes such as the types of relationships they had, the meanings they made, how they viewed mortality and reality, where they were financially in life, how they saw their bodies, and what they needed. These personal characteristics influenced each woman's view on her life as a whole and the lens in which she examined all aspects of her circumstance. Thus, within the conceptual map, the personal characteristics are seen as having influence on the entire system.

The Stage IV specific themes including mortality and reality, did not seem to add to, nor take from, the quality within life, but actually cut through the process of creating quality. The women described their thoughts of mortality and the reality of their Stage IV circumstance as a part of their identity. Thoughts regarding death were such a strong part of how they viewed their lives that they identified with them. The descriptions created a sense of living with mortality as opposed to fighting against it. These women did not have the luxury to fight against their

mortality and survive, so in turn they learned to live with it, accept it, and utilize it for preparation and as a lens for how they would view their lives. This was similar for the reality of their incurable breast cancer. Within the conceptual map, Stage IV specific characteristics are above the creation or destruction of quality of life and are described as how they define life. Life for these women was described with an identity of living with mortality and with an incurable form of breast cancer. Acceptance was a key aspect of this. The women within the sample, as has been described, all held a level of acceptance of their situation. Accepting their mortality and the reality of their disease was a way that they then viewed their life including all themes and theoretical tenets.

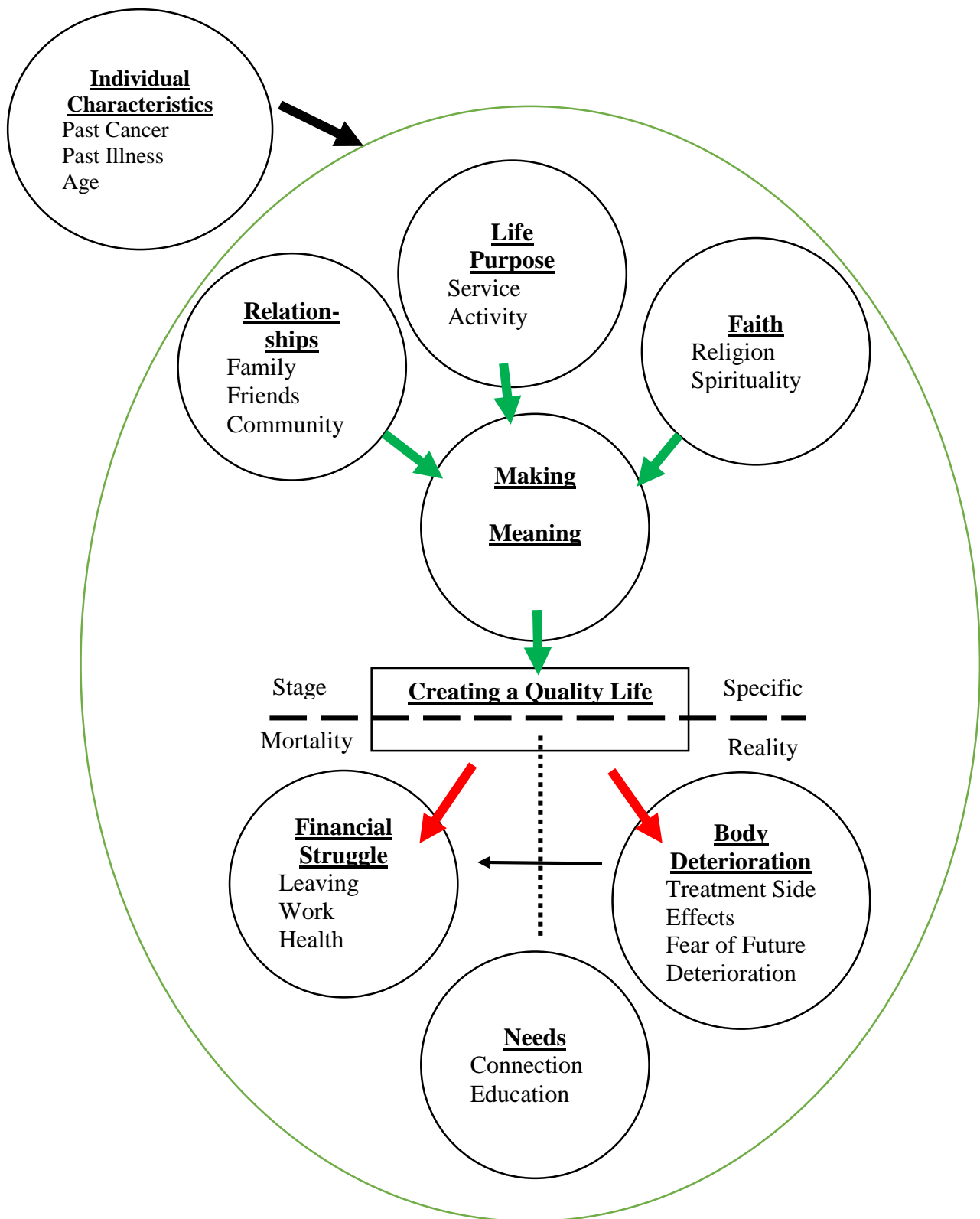
Throughout the discussions of their lived experiences with Stage IV breast cancer, two distinctive needs emerged. First, all women described a need for connecting with other women who suffer from the same disease – not just breast cancer but rather stage IV breast cancer. This description did not always come in the form of a support group. Some women were not interested in support groups or had previous negative experiences in them. Others were currently taking part in a support group and enjoyed the ability to connect in that way. Those who did not partake in support groups did describe either utilizing blogs or seeking out friends and neighbors who had had a similar diagnosis. Overall, the women spoke of a need to simply have the means to speak with other women in the same situation. Specifically, these women wanted to talk to others with Stage IV breast cancer as the specific characteristics of their diagnosis created too many differences with women with curable stages of breast cancer. Each woman spoke of needing a way to contact and connect with other women in their situation early in their diagnosis. This was commonly seen as the time of greatest need for support from others who were experiencing the same situation.

The second need that emerged was the need for education. The women in this sample each individually described the breadth of information that they needed to gather in order to understand their cancer. The amount of time that each women spent researching treatments, side effects, test results, new experimental treatments, health insurance policies, medical bills, and the like, was described as overwhelming. When the women were asked about needs that they have or have had throughout their experience, the majority of women described needing help with finding information. They described a need for someone, or some resource, to point them in the right direction, as opposed to wasting valuable time and energy. The majority of the women in the sample spent a great deal of time, on their own, researching and trying to understand what was happening with their bodies, insurance and bills. The commonality of personal information gather has been assessed in previous research. For example, a sample of 56 women at one breast cancer care center were assessed in their internet usage for information regarding their diagnosis, treatments, symptoms etc. (Nguyen & Ingledew, 2013). It was found that 71% of the sample utilized internet resources for information regarding their breast cancer. Internet based research was also common in the current sample, however women spoke to the difficulty in the process of finding accurate and reliable information. The usefulness of internet resources needs to be examined to help in the creation of specified web-based resources for this population.

Information is also needed from the cancer centers where these women visit their oncologists and receive their treatments. Currently, some breast cancer care centers are including specific patient education services, however, the efficacy of these services is just beginning to be examined. One study assessed the Breast Care Center at the University of California San Francisco (Danesh, Belkora, Volz, & Rugo, 2014). This facility has in place a Decision Supportive Services department specifically to help address the informational needs of their

breast cancer patients. This study examined the lists of questions of 59 women with metastatic breast cancer and how participants felt these questions were answered by oncologists. Through the examination of consultation notes and question lists it was found that only 37% of questions regarding prognosis were answered by physicians, 66% of quality of life questions were addressed, 81% of symptom management questions were addressed and 79% of clinical trial questions were answered (Danesh, et al.). This data shows that information on prognosis and quality of life needs were the most unanswered questions for this sample. However, the Decision Supportive Services department does implement not only oncologist consultations, but also informational videos and pamphlets for the women as supplementary informational resources. This specific type of service needs to be included in long term care for women with Stage IV breast cancer and more importantly needs to be evaluated for efficacy in order to meet the needs of these women. Resources such as this could help to address the need for education that was discussed within the current sample.

Figure 5.1: Conceptual Map of Quality of Life



Clinical Implications

The clinical implication for the current study are therapeutic and educational. The lived experiences of women with Stage IV breast cancer are unique and have not been widely researched in the current capacity. Understanding life quality, what adds to and takes away from it, and the needs of this population is of the utmost importance in the creation and reorganization of current and future resources.

Couple and family therapy/Medical family therapy. One area of the lived experience of Stage IV breast cancer that was not explored in detail was the systemic nature of the disease. Many of the women within the current sample briefly discussed how their cancer had negatively affected their families, describing emotional responses such as devastation, sadness, denial, and the like. These responses to the cancer were common among the population due to the severity of the disease and the reality of the situation that these women were going to die sooner than expected. Family members, in particular, had difficult reactions to their loved one slowly dying. However, not one of the women in this study utilized therapy or mental health resources for their families. Many reported not considering finding help for their families or not knowing that family therapy was an option. Additionally, only two women spoke of going to a therapist to help with the emotions of their cancer and neither experience was described as highly beneficial. This is a call to action for individuals within the mental health field who are specially trained in systems thinking and relational therapy. The women within this sample who did not utilize mental health resources were not aware of any near them, reported them to be too expensive or had never thought about utilizing them as an option. This is a population that is living with a complex set of challenging and demanding circumstances. Women who are living with this incurable disease are struggling with body deterioration, fears of the future, stress, and the like.

These women, however, report receiving support from their communities, friends and family. However, the unknown aspect of this disease is whether or not family members are receiving the same level of support. It is clear that family members are having strong emotional reactions, it is not clear how they are handling these emotions and if they are communicating openly about them. This is an area where relationally trained therapists are needed. More specifically, relational therapists with a medical knowledge of this disease would be beneficial for this population. Medical family therapists could be utilized at locations convenient to doctors' appointments or treatments for the women and they would have a unique understanding of the medical stress of the disease but also have the ability to help with the relational difficulties that these women experience. Based on the current sample, mental health resources, specifically those who are trained in systems, are not a known resource. It is up to the field of couple and family therapy and medical family therapy to understand the dynamics of this illness and to present themselves as a resource to cancer centers, doctors' offices, nursing staff, and the like.

Group therapy. An additional clinical implication for this population is the creation and implementation of specialized group therapies and an increase on availability of support groups. The women with in the current study were not in consensus about the benefit of supportive group resources. Few had been involved in a specialized support group and many stated that they had negative experiences with them in the past. The negative experiences came from groups that were for all stages of breast cancer or from past experiences with other types of support groups. However, each participant discussed a need for connection with others that had a Stage IV diagnosis. This leads to a call to action for therapists trained in group therapy and with a medical knowledge to be more active in supportive group resources for this population. Medical family therapists would be an ideal field for these groups to arise from. The one active support group

within the Atlanta, GA area that was discussed within the interviews was successful and the women spoke highly of the connection that they were able to build with each other. Death of group members was, however, a realistic and difficult part of this group experience. There is a need for these types of groups to be organized and run by professionals who possess the knowledge to manage groups that will include medical knowledge, relationships, and grief and loss. Few of these groups exist within the areas that the participants lived and all spoke of a need for connection. This is an area of growth for the medical and therapeutic field.

The distinct systems training and theoretical orientations in the field of couple and family therapy/medical family therapy lend itself to be uniquely qualified to handle the complexity of how this disease affects the individual woman, the individual members of the family and the connections between each family member. Couple and family therapists are trained in working with whole family systems and would have the ability to value each members experience while working with the entire family to stay connected and help to cultivate a quality family life.

Education. The second area that has clinical implication is within education. One of the commonly described needs of this sample was the need for organization and access to information. When asked about what this sample needed or currently needs, overwhelmingly the participants spoke of the difficulty with gaining the knowledge to navigate the disease. There is a lack of organization of information and confusion about where to find it. As has been previously stated, the amount of information that these women need to learn and understand is intimidating. There is a need to have staff (i.e. social workers, medical family therapists) who have to ability to help navigate the information that is needed. Although each diagnosis is different and will bring with it individualized treatments, physical and psychological symptomology, it would be beneficial for these women to have an individual or central resource to contact that would help to

point them in the right direction. Whether it is giving them a list of websites to visit, books to read or other women to connect to, there needs to be more organization for how these women are receiving information. This is a call to action for medical offices and cancer centers to include staff who can educate these women and help them to obtain the right resources. It is essential that information be made available to these women. The majority of the women within this study had spent many hours researching, studying, and searching for information on the internet. This time could be shortened if there were a larger scale resource with a collection of information, and/or a person that could be contacted to help them gain the best and most accurate information possible.

Limitations

The current study has three limitations. First, this study was limited by a small sample size. Although saturation of the experience was met, this was a difficult population to gain access to and thus this study is limited to the description of ten women's experience and not generalizable beyond this sample. Due to the difficulty in access, the interviews were also limited to phone contact. Eight of the 10 women were interviewed over the phone. This was due to location of the women and physical inability to meet face to face. Although the phone interviews were rich in information, there may have been more emotional expression if the researcher would have been able to meet the women face to face.

Second, the population of women that chose to participate within this study were all in relatively good physical condition. Although the women had been living with the disease for an average of 6 years, no individual woman was near the end of life. All the women were experiencing success in treatments and still maintained a functional daily life. This created difficulty for the women to project how their quality of life would be in the future when they are

suffering from more physical ailments and treatments are not as successful. Thus, this description is limited to a sample of women whose treatments were working to slow the progression of their disease. As many women alluded, quality of life was expected to change as the disease progressed further. Not having a broad sample of women at different progressions of the disease limits the ability to understand how the experience and life quality changes over time.

The third limitation is reflected in the lack of systemic focus. The interviews were individually focused and more specifics regarding family member reactions, relationship dynamics and communication within the family is needed to create a deeper understanding of the experience of Stage IV breast cancer. Although the current study is the first of its kind and has produced a rich understanding of the lived experience of Stage IV breast cancer, it is limited in the ability to speak to the systemic and relational aspects of the disease.

Future Research

The future research for this topic is directly linked to the limitations of this study. First, future research needs to broaden the search for women with differing progression of this disease. Although it will be challenging to gain participation from women towards the end of life, perhaps looking into hospice facilities could be an option. It is important to understand the future concerns of this population and how quality of life is achieved when activity and physical ability is limited. It is hypothesized that the process of making meaning will change and meaning may come from different sources than those who are still physically able to function.

Future research also need to focus on the systemic and relational aspect of this disease. As has been shown, there are many emotional reactions of family members, however, due to the limitation of this study, little is understood regarding the communication and familial processing

of this incurable disease. The fact that women can live many years with this disease also lends itself to a need for understanding how families move through life transitions while treating Stage IV breast cancer. Many women in the current study are watching their children graduate and sending them to college, while negotiating different phases of their marriages. These dynamics are all experienced with the unique lens of mortality and the reality of the Stage IV disease. How this influences family function is a part of the experience that needs to be examined.

Conclusion

Women with Stage IV breast cancer are courageous and strong. They are living long lives, despite their illness and are doing so with a high quality of life. They live their lives from one treatment to the next and in a timespan that lasts from one PET scan to the next. Has the cancer spread? Is the tumor larger? Will it be found in a different part of my body? These are questions that these women ask with each doctors' appointment and with each passing year. However, these women are also creating a life that is worth living. Through family, faith, and finding a purpose to their lives, these women are showing strength that few can understand. This is not a sickly group of women struggling to wake up each morning. This is a minority group of women living in a dominant culture where they are not understood and there are limited resources for them. However, this is a group of women that strives to make the best out of each day and fill their lives with beauty, love, and enjoyment, despite the many hardships they face. This is a little known population that has been looked down upon by the larger culture, but that has shown great resiliency. It has been my personal pleasure to have met these women and had the privilege of telling their stories. It has inspired me to continue the future research to further understand this experience and to create better resources for this population.

APPENDICES

APPENDIX A

Table 1A: Stage Designation for Breast Cancer

Stage	Primary Tumor (T)	Regional Lymph Nodes (N)	Distant Metastasis (M)
0:	Carcinoma present but at primary location.	No regional lymph node metastasis.	No distant metastasis.
I:	Tumor more than 0.1cm but not more than 0.5 cm.	No regional lymph node metastasis.	No distant metastasis.
IIA:	No evidence of primary tumor.	Metastasis in movable ipsilateral axillary lymph nodes.	No distant metastasis.
	Tumor more than 0.1cm but not more than 0.5 cm.	Metastasis in movable ipsilateral axillary lymph nodes.	No distant metastasis.
	Tumor more than 1cm but not more than 2cm	No regional lymph node metastasis.	No distant metastasis.
IIB:	Tumor more than 2cm but not more than 5cm	Metastasis in movable ipsilateral axillary lymph nodes.	No distant metastasis.
	Tumor more than 5cm	No regional lymph node metastasis.	No distant metastasis.
IIIA:	No evidence of primary tumor.	Metastases in ipsilateral axillary lymph nodes fixed or in clinically apparent internal mammary nodes.	No distant metastasis.
	Tumor more than 0.1cm but not more than 0.5 cm.	Metastases in ipsilateral axillary lymph nodes fixed or in clinically apparent internal mammary nodes.	No distant metastasis.

Table 1A (cont'd)

	Tumor more than 2cm but not more than 5cm.	Metastases in ipsilateral axillary lymph nodes fixed or in clinically apparent internal mammary nodes.	No distant metastasis.
	Tumor more than 5cm.	Metastasis in movable ipsilateral axillary lymph nodes.	No distant metastasis.
	Tumor more than 5cm.	Metastases in ipsilateral axillary lymph nodes fixed or in clinically apparent internal mammary nodes.	No distant metastasis.
IIIB:	Tumor of any size with direct extensions to chest wall or skin.	No regional lymph node metastasis.	No distant metastasis.
	Tumor of any size with direct extensions to chest wall or skin.	Metastasis in movable ipsilateral axillary lymph nodes.	No distant metastasis.
	Tumor of any size with direct extensions to chest wall or skin.	Metastases in ipsilateral axillary lymph nodes fixed or in clinically apparent internal mammary nodes.	No distant metastasis.
IIIC:	Any T	Metastasis in ipsilateral infraclavicular lymph node(s), or in clinically apparent ipsilateral internal mammary lymph node(s) and in the presence of clinically evident axillary lymph node metastasis; or metastasis in ipsilateral supraclavicular lymph node(s) with or	No distant metastasis.

Table 1A (cont'd)

		without axillary or internal mammary lymph node involvement.	
IV:	Any T	Any N	Distant metastasis.

(Singletary, Allred, Ashley, Bassett, Berry, Bland, Borgen, Clark, Edge, Hayes, Hughes, Hutter, Marrow, Page, Recht, Theriault, Thor, Weaver, Weiland, & Greene, 2003).

APPENDIX B

WOMEN WITH METASTATIC BREAST CANCER

WE NEED YOUR HELP!

This research study will explore the experience of women with metastatic breast cancer and the needs of this population of women. The invaluable information that YOU can give will help to inform future and current psychosocial interventions to help benefit women in your situation.

Please help to inform interventions for women with metastatic breast cancer.

Your experience is truly important!

You are eligible if:

- You have a current diagnosis of Stage IV, metastatic breast cancer.
- You are proficient in English.

Participation includes:

- A 1-2 hour individual interview.
- A two hour focus group with 6-8 other women with a Stage IV diagnosis.

PARTICIPANTS WILL RECEIVE A \$25 VISA GIFT CARD

**If you are interested or would like to know more about this study please
contact**

Karly J. Downs, M.A.,

by telephone at 678-800-6810

or by email at karlydowns.research@gmail.com

Thank you for your consideration in helping women with metastatic breast cancer.

APPENDIX C

Research Participant Informed Consent

Introduction

Karly J. Downs, M.A., Ph.D candidate in Couple and Family Therapy at Michigan State University is conducting a study entitled, Understanding the Experiences of Stage IV Breast Cancer: A Qualitative Inquiry of Women with a Stage IV Diagnosis. This study focuses on understanding the experience and needs of women with metastatic breast cancer.

Researchers are required to provide a consent form to inform you about the study, to explain risk and benefits of participation and to empower you to make an informed decision. You should feel free to ask the researcher any questions you may have.

Purpose of Research

You have volunteered as someone who may be willing to participate in this important research. Your experience with breast cancer will be greatly beneficial to the breast cancer literature and will help to inform future interventions specific to a population of women with metastatic breast cancer. Your knowledge will lead to further understanding of the specific needs of women with metastatic breast cancer and will be used to inform current and future psychosocial interventions. Your participation is completely voluntary. Declining to participate in this research project will not affect you in any way.

Procedures and Participation

Participation involves two interviews. First you will be asked to participate in a 1-2 hour individual interview to discuss your experience with metastatic breast cancer. Second you will be asked to participate in a 2 hour focus group including yourself and 6-8 other women who share a diagnosis of metastatic breast cancer. This focus group will explore the needs of women with metastatic breast cancer and their thoughts on and experiences with psychosocial interventions.

By agreeing to participate in this study, you will be expected to complete the following:

- Sign this informed consent form.
- Fill out a demographic form.
- Schedule and participate in a 90 minute to 120 minute interview and schedule and participate in a 120 minute focus group.
- Agree the interview and focus group will be audio tape recorded.
- Understand you will receive a monetary incentive of a \$25 dollar Visa gift card at the focus group interview.

It is important that you are aware that participation in this research is voluntary and you may stop the interview or decline participation in the focus group at any time. The location of the interview will be your choice and the focus group will be in private location.

I agree to allow audio taping of the interview.

_____Yes _____No Initials_____

Risks and Benefits

There are minimal risks for participation in this study. There is potential for discomfort associated with providing information about your experience with metastatic breast cancer. It is possible you may be asked about sensitive issues that could evoke negative responses. If additional support is needed, the researcher will provide you with the names of local mental health resources.

The benefits to you for participating in this study are indirect, as the information provided by you will benefit the overall population of women with metastatic breast cancer in gaining help and resources that meet the specific needs of this population.

Women in your situation will benefit from the knowledge that you contribute, as this study will be published to inform health care professionals to better serve women with metastatic breast cancer.

YOU MAY REFUSE TO CONTINUE YOUR PARTICIPATION IN THIS STUDY AT
ANYTIME.

Confidentiality

Your confidentiality will be protected to the maximum extent allowable by law. The individual interview and focus group will both be audio-taped. However, reasonable and appropriate actions will be taken to keep your information confidential. No identifying information will accompany any materials. Names will not be used in the transcription of the interviews and focus groups. Recordings will be marked with identification numbers and coded. All data will be stored in a locked filing cabinet. Audio recordings will be erased after transcription is completed. The researchers and IRB will have access to the code, but again no identifying information will be placed on the transcriptions. The results of this study may be published or presented at professional meetings, but the identities of all participants will remain anonymous.

Rights to Participate, Say No, or Withdraw

Participation in this research project is completely voluntary. You have the right to say no to participation. You have the right to change your mind at any time and withdraw participation at any point within the study process. You may choose not to answer specific questions. Choosing not to participate, withdraw, or not answer specific questions, will not have negative consequences in any way.

Compensation for Participation

You will be compensated for your participation in this study. You will receive a \$25 Visa gift card for your participation in this study that will be given at the time of the focus group interview.

Questions Regarding Research

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researcher, Karly J. Downs.

Karly J. Downs

karlydowns.research@gmail.com

678-800-6810

Questions about your Rights as a Research Participant

If you have questions regarding your rights as a participant in a research project, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or email irb@msu.edu or regular mail at 207 Olds Hall, MSU, East Lansing, MI 48842.

By signing this form, you acknowledge that your participation in this research study is voluntary and that you agree to participate in this research.

I voluntarily agree to participate in this research study:

Research Participant

Date

I certify I have explained the research to _____ and believe she understands and has agreed to participate freely. I agree to answer any additional questions when they arise during the research or afterward.

Signature of Researcher

Date

You will be given a copy of this form to keep.

APPENDIX D

Participant Demographic Information

Participant Number: _____

Age: _____ DOB (Month/Year): _____

Date of Diagnosis (Month/Year): _____

Please list all immediate family members below (first names only):

EXAMPLE: BILL Relation: HUSBAND Age: 51

_____ Relation: _____ Age: _____

_____ Relation: _____ Age: _____

_____ Relation: _____ Age: _____

_____ Relation: _____ Age: _____

_____ Relation: _____ Age: _____

What is your employment status (please circle)?

Employed full time Employed part-time Retired Unemployed Volunteer

Other _____

Where are/were you employed? _____

Highest level of education obtained? _____

Race: _____

Ethnicity: _____

Spiritual/Religious

Affiliation: _____

APPENDIX E

Individual Interview Guide

Introductory Statement:

Hello and thank you for meeting me for this interview today and agreeing to be a part of the research that I am conducting on women with stage IV breast cancer. I appreciate your willingness to take time out of your schedule to give insight into this topic. Your experience with breast cancer is invaluable and I encourage you to be open and honest with your answers.

The interview will consist of several questions that I would ask you to answer based on your experiences. As the interview unfolds I may ask further clarifying questions. The interview will last anywhere from two to two and a half hours. Please let me know if you have any questions throughout the interview. If at any time you wish to stop the interview please let me know. Your participation is voluntary. Thank you again for your participation.

Question #1

What has been your experience with cancer from diagnosis to today?

Question #2

What have been the most significant milestones throughout your cancer experience?

Probes:

- Why were these significant for you?

Question #3

How have your past experiences (e.g. your childhood, values, life experiences), prior to your diagnosis, influenced your cancer experience?

Question #4

Tell me about the things in your [environment, culture, community, family], that affected your cancer experience.

Question #5

How did you react to your diagnosis?

Question #6

Have you come to terms with your diagnosis?

Probe:

- If yes, how? If no, describe what you are struggling with?

Question #7

How did you adapt to the physical symptoms of the disease and the effects from treatments?

Question #8

Describe your emotional reactions to the diagnosis?

Question #9

What have your psychological responses been to the diagnosis?

Probe:

- How have you overcome these?

Question #10

How have family, friends and community supports contributed to your experience with your illness?

Question #11

What role has spirituality played in living with cancer?

Question #12

How has your work and recreational life been effected by your cancer?

Probe:

- How have you responded to this?

Question #13

What have you done individually to cope with your disease?

Question #14

Describe your quality of life.

Question #15

How would you rate your life quality on a scale from 1-10?

Probe:

- What would need to be present in your life to make it better?

Question #16

How do you create balance in your life, personally, socially, spiritually, etc.?

Question #17

What are your thoughts and feelings regarding life and death?

Probe:

- Has meaning in life changed for you?
- Have your thoughts on death changed?

Question #18

What are the most important needs that you have had in your experience with breast cancer?

Question #19

When you received your diagnosis, what did you wish you knew then that has helped you along the way to overcome the challenge of cancer?

Question #20

Have you utilized mental health or psychosocial resources?

If “yes”: What psychosocial interventions have you participated in (e.g. therapy, groups, family therapy, consultation with religious figures)?

If “no”: Why not?

Question #21

What have you found to be most beneficial from the interventions you participated in? OR What types of resources do you think would be beneficial to participate in?

Question #22

Please think about your quality of life. Is there anything that you wish you had or that you currently have that could or currently does increase the quality of your life?

APPENDIX F

Confidentiality Agreement

I _____ understand that information and identities of all participants will be kept strictly confidential and will not be released to anyone. Throughout the process of transcription, all audio and word documents will be kept in a secure location where only I have access. No outside persons will hear nor read the data being transcribed. Once transcriptions are completed all audio and word files will be given to Karly J. Downs and subsequently deleted from my possession. By signing this document I agree to all confidentiality guidelines and understand my role in keeping the data secure.

Signature

Date

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